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Preimplantation Genetic Diagnosis: From Preventing Genetic Disease to Customizing Children. Can the Technology be Regulated Based on the Parents' Intent?

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PREIMPLANTATION GENETIC DIAGNOSIS: FROM PREVENTING GENETIC DISEASE TO CUSTOMIZING CHILDREN. CAN THE TECHNOLOGY BE REGULATED BASED ON THE PARENTS' INTENT?

I. INTRODUCTION

In 1997, Coumbia Pictures released the motion picture *Gattaca*. The film, set in the "not too distant future," depicted a society in which parents used technology to select every possible trait for their children before the children were born.[1] One of the most memorable lines from the movie is, "People used to say that a child conceived in love has a better chance of happiness. They don't say that anymore."[2] Instead, children who were born without the benefit of such technology were referred to as "degenerates" and faced discrimination.[3] Although we do not yet live in such a society, a recent advance in genetic and reproductive technology, called preimplantation genetic diagnosis ("PGD"), has led to the following scenarios.

Scenario One: Imagine yourself in the position of Colorado couple Jack and Lisa Nash, who learned that their daughter, Molly, had been diagnosed with the rare and deadly genetic disease Fanconi's anemia[4] and was likely to die by age seven.[5] The desperate parents were willing to do whatever was necessary to save her life, but Molly was an only child and the best treatment

1. GATTACA (Columbia Pictures 1997).

2. *Id*.

3. *Id*. Ethan Hawke plays the main character in the film. He was the first child in his family and was born without the benefit of the technology. After he was born with a genetic heart condition, his parents used the technology before the birth of their second child. A poignant moment occurs when Hawke's character says, "I'll never understand what possessed my mother to put her faith in God's hands, rather than the local geneticist." *Id*.

4. Fanconi's anemia is defined as "a rare, usually congenital disorder transmitted as an autosomal-recessive trait, characterized by aplastic anemia in childhood or early adult life, bone abnormalities, chromatin breaks, and developmental anomalies. Children begin to show symptoms between 4 and 12 years of age." MOSBY'S MEDICAL, NURSING, & ALLIED HEALTH DICTIONARY 615 (5th ed. 1998); *see also* Susan M. Wolf et al., *Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor: Issues, Guidelines & Limits*, 31 J.L. MED. & ETHICS 327, 328 (2003) (describing Fanconi's anemia as a "rare fatal disorder that is associated with bone marrow failure, leukemia, and marked cancer predisposition and is inherited in an autosomal recessive fashion").

5. Rick Weiss, *Test-Tube Baby Born to Save Ill Sister: Genetic Selection by Colorado Parents May Herald an Era*, WASH. POST, Oct. 3, 2000, at A1.

would be to replace her faulty bone marrow cells with the healthy cells of a perfectly-matched sibling.[6] To save Molly, the Nashes used in-vitro fertilization ("IVF")[7] and PGD to conceive another child who would be a healthy and Human-Leukocyte Antigen ("HLA") tissue-matched donor.[8] With PGD, researchers test a single cell for a genetic disorder from embryos created through standard IVF and implant only those cells that are free of the disorder into the woman's uterus.[9] In the Nash case, two of fifteen embryos were perfect tissue matches after several attempts, but only one was healthy enough to be transferred into Lisa's womb.[10] Fortunately, that embryo implanted properly, and baby Adam was born on August 29, 2000.[11] After Adam was born, doctors saved the blood cells from his umbilical cord and infused them into Molly's circulatory system approximately one month later.[12] As of 2003, the transplant had succeeded, as Molly's hematopoietic and immune systems were normal three years after the procedure had taken place.[13]

Scenario Two: Next imagine yourself in the position of California couple Jeffrey and Melanie Sowers. Shortly after the couple's first child was born, Jeffrey was diagnosed with myotonic dystrophy, a common form of muscular dystrophy.[14] The Sowers wanted another child, but did not want to risk the 50 percent chance that their children could also get the debilitating disease.[15] When the couple learned of PGD, Mrs. Sowers began the procedure to avoid

6. *Id.*; *see* Wolf et al., *supra* note 4, at 328 (noting that hematopoietic stem cell transplant is the only therapeutic approach with proven success in reversing the bone marrow complications of Fanconi's anemia. The morbidity and mortality associated with this kind of transplant are substantially lower when using a sibling donor who is Human-Leukocyte Antigen ("HLA") tissue-matched to the ill child, as compared to an unrelated donor.).

7. IVF is defined as

> a method of fertilizing human ova outside the body by collecting the mature ova and placing them in a dish with a sample of spermatozoa. After an incubation period of 48 to 72 hours, the fertilized ova are injected into the uterus through the cervix. The procedure takes from 2 to 3 days.

MOSBY'S, *supra* note 4, at 870.

8. Wolf et al., *supra* note 4, at 328.

9. For a simple overview of PGD, see generally Bonnie Steinbock, *Preimplantation Genetic Diagnosis and Embryo Selection*, *in* A COMPANION TO GENETHICS 175 (Justine Burley & John Harris eds., 2002).

10. Weiss, *supra* note 5, at A1.

11. *Id.*

12. *Id.* Umbilical cells are used because "[r]esearch has shown that [these cells] . . . can travel to a recipient's bone marrow and repopulate the marrow space with healthy cells." *Id.*

13. Wolf et al., *supra* note 4, at 328.

14. Amy Dockser Marcus, *Ensuring Baby Will Be Healthy: Embryo's Screening Gains in Popularity, Controversy; Choosing A Child's Gender*, WALL ST. J. EUR., July 26, 2002, at N3, *available at* 2002 WL-WSJE 22218003.

15. *Id.*

passing on the genetic disease to any future children.[16] PGD is widely used by couples who know that they have a risk of passing along diseases such as Tay-Sach's, hemophilia, Gaucher's disease, sickle cell disease, Huntington's, and other genetic conditions.[17] The couples use PGD to detect those embryos that carry the genetic illness.

Scenario Three: Finally, imagine yourself in the position of a couple that chooses to use PGD for a non-medical purpose that is not described above. Suppose you already have three boys, and would like to guarantee that your next child is a girl, or vice versa. You might also want to attempt to give your child every possible advantage; so you use PGD to select for traits such as intelligence, athletic ability, or musical inclination. PGD could be used in such a way that will allow parents the unprecedented ability to choose the traits of their children, for any reason or no reason at all.[18]

This Comment will address the various ways that PGD can be used and examine how the technology is being regulated internationally. To date, the United States has not adopted any sort of regulation or control over the procedure. Section II traces the development of PGD and discusses the controversies surrounding both the therapeutic and non-therapeutic uses of the technology. Section III examines how other countries regulate PGD and assisted reproductive technologies ("ARTs"). Section IV considers whether the United States can create legislation that regulates PGD and authorizes its use for only medical and therapeutic purposes, such as the first two scenarios described above. This Comment argues that, despite the value given to procreative liberty in this country, the United States must implement such legislation and that it is permissible to do so based on the couple's intent and purpose in obtaining the procedure.

16. *Id*.

17. *Id*.; *see also* Richard J. Tasca & Michael E. McClure, *The Emerging Technology and Application of Preimplantation Genetic Diagnosis*, 26 J.L. MED. & ETHICS 7, 7 (1998).

18. *See* MAXWELL J. MEHLMAN, WONDERGENES: GENETIC ENHANCEMENT AND THE FUTURE OF SOCIETY 2 (2003) ("Genetic tests will soon be developed that can identify embryos or fetuses not just with genetic abnormalities, but with desirable physical or mental traits, enabling parents to decide which ones to implant in the womb or bring to term."); *see also* FRANCIS FUKUYAMA, OUR POSTHUMAN FUTURE: CONSEQUENCES OF THE BIOTECHNOLOGY REVOLUTION 75 (2002) (noting that the first step toward giving parents greater control over their children's genetic makeup will come from PGD. "In the future it should be routinely possible for parents to have their embryos automatically screened for a wide variety of disorders, and those with the 'right' genes implanted in the mother's womb.").

II. THE BACKGROUND, DEVELOPMENT, AND ETHICS OF PGD

A. Brief Background of the Technology

PGD was first performed in 1989 and was used to avoid creating a child inflicted with a genetics-based disorder.[19] PGD has since been successfully applied to a variety of genetic diseases, either single gene disorders or chromosomal abnormalities.[20] Before PGD was used, prenatal testing was performed during the first trimester by using chorionic villus sampling,[21] by ultrasound,[22] or by amniocentesis.[23] PGD is most commonly used by couples who have had one child affected with a genetic disorder and/or one or more termination(s) of pregnancy following the conventional testing described above.[24] PGD reduces the chance that parents will be faced with the difficult decision of whether to terminate a pregnancy by preventing gestation of affected embryos.[25] The possibility of saving a couple from enduring a series of terminated pregnancies is an obvious advantage of PGD.[26] The terminations can be very physically and psychologically stressful because "each aborted fetus is potentially a wanted child."[27] PGD allows couples to create their family with increased confidence that they will neither give birth to an affected child nor subject themselves to the chance of having to terminate a pregnancy.[28]

19. Wolf et al., *supra* note 4, at 327.

20. American Society for Reproductive Medicine, *Fact Sheet: Preimplantation Genetic Diagnosis* (Dec. 1996), *at* http://www.asrm.org/Patients/FactSheets/PGD-Fact.pdf (last visited Sept. 10, 2004) [hereinafter *ASRM Fact Sheet*]. The American Society for Reproductive Medicine ("ASRM") notes that PGD can now detect Cystic Fibrosis, Fragile X syndrome, Down syndrome, Tay-Sachs disease, and Hemophilia A, among others. *Id*.

21. Chorionic villus sampling is defined as a

> sampling of chorionic villi from the villous areas of the chorion, a procedure used for prenatal diagnosis at nine to 12 weeks of gestation. A catheter is inserted either through the cervix or through the abdominal wall and fetal chorionic villus tissue for analysis is aspirated under ultrasonic guidance. This has been used for the prenatal diagnosis of fetal trisomies, hemoglobinopathies, and biochemical disorders. It allows first trimester diagnosis and direct chromosomal and biochemical analysis but does not screen for neural tube defects or certain other anomalies; some of those may be identified by maternal serum and amniotic fluid alphafetoprotein measurements.

MILLER-KEANE ENCYCLOPEDIA & DICTIONARY OF MEDICINE, NURSING, & ALLIED HEALTH 1578–79 (7th ed. 2003).

22. Ultrasound is defined as "sound waves at the very high frequency of over 20,000 kHz (vibrations per second). Ultrasound has many medical applications, including fetal monitoring, imaging of internal organs, and, at an extremely high frequency, the cleaning of dental and surgical instruments." MOSBY'S, *supra* note 4, at 1672.

23. Jason Christopher Roberts, *Customizing Conception: A Survey of Preimplantation Genetic Diagnosis and the Resulting Social, Ethical, and Legal Dilemmas*, 2002 DUKE L. & TECH. REV. 12, 7 (2002), *available at* http://www.law.duke.edu/journals/dltr/articles/PDF/2002dltr0012.html. Amniocentesis is defined as

PGD allows dissection and testing of a single cell from an eight-cell embryo.[29] The process involves ovarian hyperstimulation, oocyte (egg) retrieval, and IVF.[30] Forty-eight to seventy-two hours later, the embryo usually consists of six to ten cells called blastomeres.[31] A blastomere (single cell) is then removed through a biopsy and DNA is extracted, amplified by polymerase chain reaction, and analyzed.[32]

A diagnosis is typically obtained within twenty-four hours, and only the unaffected embryos are transferred into the woman's uterus, with the hopes of initiating pregnancy.[33] The American Society for Reproductive Medicine ("ASRM") cautions that not all disorders can be diagnosed by PGD.[34] It is imperative that parents understand that PGD "does not guarantee that the child will be free of [all] genetic or congenital conditions."[35] PGD can only verify that the child will be free of conditions for which testing is done.[36] Although

> an obstetric procedure in which a small amount of amniotic fluid is removed for laboratory analysis. It is usually performed between the sixteenth and twentieth weeks of gestation to aid in the diagnosis of fetal abnormalities. . . . With the use of ultrasound scanning techniques the position of the fetus and the location of the placenta are determined. The skin on the mother's abdomen is aseptically prepared, and a local anesthetic is usually injected. A needle attached to a syringe is introduced into a part of the uterus where there is the least chance of perforating the placenta or scratching the fetus.

MOSBY'S, *supra* note 4, at 75–76.

24. Heather Draper & Ruth Chadwick, *Beware! Preimplantation Genetic Diagnosis May Solve Some Old Problems but It Also Raises New Ones*, 25 J. MED. ETHICS 114, 114 (1999).

25. Wolf et al., *supra* note 4, at 327; *see also* Tasca & McClure, *supra* note 17, at 7 (noting that couples who only use chorionic villus sampling or amniocentesis are more likely to decide whether to abort a fetus at a more advanced developmental stage).

26. Draper & Chadwick, *supra* note 24, at 114.

27. *Id*. *But see* Jeffrey R. Botkin, *Ethical Issues and Practical Problems in Preimplantation Genetic Diagnosis*, 26 J.L. MED. & ETHICS 17, 20 (1998). Botkin states that the psychological reactions to PGD remain to be evaluated. *Id.* While PGD is not anticipated to carry the same psychological effects associated with miscarriages or other losses, there are still questions to consider. *Id*. Such issues include the psychological implications of going through IVF and then discarding affected embryos, whether women think about the children that might have been, and whether the embryos become lost children in the couple's minds with time. *Id.*

28. Draper & Chadwick, *supra* note 24, at 114.

29. Wolf et al., *supra* note 4, at 328.

30. *Id*.

31. *Id*.

32. *Id*.

33. *ASRM Fact Sheet*, *supra* note 20.

34. *Id*.

35. Botkin, *supra* note 27, at 19. The author describes such a child as a "perfect" baby. *Id*. PGD is not useful for predicting congenital diseases because these malformations "do not have their origins in single-gene defects or in detectable chromosomal aberrations." *Id.*

36. *Id*. (also noting that PGD alone will not reduce the risk of offspring with conditions such as spina bifida, anencephaly, hypoplastic left heart, renal agenesis, and other conditions because

PGD has helped many families and has ensured the health of both future and existing children, the technology is not perfect. Mistakes in diagnosis have occurred, including one highly-publicized case where parents sued the institution where they underwent PGD after their child was born with cystic fibrosis.[37]

B. General Opposition to PGD

1. Concern of Oppressing People with Disabilities

There is opposition to PGD because it identifies and discards embryos that are affected by a genetic disease.[38] Yet, couples do not use PGD simply to be informed about the genetic nature of their embryos; the explicit purpose for most couples is to transfer healthy embryos to the woman and discard those determined to be affected with unwanted diseases.[39] Prenatal diagnosis in general is criticized because it sends a message of rejection to people with disabilities and could lead to decreased tolerance of disability and could encourage embryos and fetuses with disabilities to be eliminated rather than welcomed into the world.[40] Some fear that parental reproductive decisions will be influenced by the "key social pressure" of oppressing people with disabilities.[41] Able-bodied people may receive negative images of people with disabilities and can be generally misinformed about what their lives are like.[42]

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the malformations in these conditions often do not have their origins in single-gene defects or in detectable chromosomal aberrations); *see also* Genetics and Public Policy Center, Berman Bioethics Institute, John Hopkins University, *Preimplantation Genetic Diagnosis: A Discussion of Challenges, Concerns, and Preliminary Policy Options Related to the Genetic Testing of Human Embryos*, 6 (2004), *at* http://www.dnapolicy.org/downloads/pdfs/policy-pgd.pdf [hereinafter *A Discussion of Challenges*] (noting that it is recommended that PGD results be confirmed by subsequent prenatal tests because errors can be made when testing the embryos).

37. See Doe v. Illinois Masonic Med. Ctr., 696 N.E.2d 707 (Ill. App. Ct. 1998) (rejecting the parents' claim of "loss of consortium" and the child's claim of "wrongful life" and ultimately concluding that the defendants could not be held legally liable).

38. *See generally* Steinbock, *supra* note 9, at 178–81. "PGD and embryo selection, just as much as prenatal diagnosis and abortion, imply that it is better that children who have disabilities are not born." *Id.* at 180.

39. Botkin, *supra* note 27, at 19.

40. *Id.* at 22; *see also* Draper & Chadwick, *supra* note 24, at 115 (questioning whether we should "eradicat[e] difference or intolerance to indifference"); Steinbock, *supra* note 9, at 178 (noting that a primary aim of prenatal diagnosis is the avoidance of a child with a disability).

41. David S. King, *Preimplantation Genetic Diagnosis and the 'New' Eugenics*, 25 J. MED. ETHICS 176, 178 (1999). Parents are likely to select offspring that conform best to social norms regarding health, physical ability, appearance, and aptitude. *Id.* at 181.

42. *Id.* at 178 (noting that genetic counselors rarely put potential parents in contact with people who actually are affected by the particular disorder in question); *see also* Steinbock, *supra* note 9, at 180 ("Disability rights activists have performed a much-needed service in making the

Furthermore, parents are acutely aware of the more material aspects of disability oppression, such as insufficient welfare provisions, lack of access, discrimination, and increased financial burdens.[43] These social pressures can result in a systematic bias against the birth of genetically-disabled children.[44]

Advocates for the disabled do not want to send a message that a life with a disability is not worth living at all or that these traits are inferior.[45] Advocates of PGD counter that the severity of disorders and disabilities are very different, as some people who are affected have little cognitive ability and are unable to understand their situation.[46] Thus, couples may want to use PGD to prevent their future children from such suffering. There is speculation that continuing a pregnancy with an affected embryo could be abolished because most people would not want to implant an embryo that will develop into a child with a genetic disorder.[47]

2. Opposition from Anti-Abortion Activists

One of the most common arguments against using PGD to screen for serious genetic diseases is related to the moral status of the embryo.[48] There are several different views as to the moral status of the human embryo and fetus:

larger community aware that most people with disabilities find their lives rewarding and worthwhile.").

43. King, *supra* note 41, at 178.

44. *Id*. (characterizing this bias as "eugenic" and noting that the purpose of PGD is eugenic because its aim is to reduce the number of births of children with congenital and genetic disorders).

45. *See* Roberts, *supra* note 23, at 13; *see also* Steinbock, *supra* note 9, at 179 (noting that disability rights advocates claim that many disabilities are largely socially constructed and therefore "[t]he appropriate response is to change society's attitude toward disability, not to try to get rid of disabled individuals"). These activists also emphasize that not all disabilities are detected by prenatal screening. *Id*. "As long as there are going to be people with disabilities, it is argued, an attitude of inclusion is better than an attitude of removal." *Id*.

46. Rebecca Knox, Comment, *Preimplantation Genetic Diagnosis: Disease Control or Child Objectification?*, 22 ST. LOUIS U. PUB. L. REV. 435, 440 (2003).

47. King, *supra* note 41, at 180; *see also* Steinbock, *supra* note 9, at 179 (suggesting that prenatal screening increases intolerance of imperfection by leading parents to expect a "perfect baby"). *But see* Botkin, *supra* note 27, at 23 ("Current experience indicates that society can simultaneously promote respect and opportunity for the disabled while enabling couples to prevent the birth of a disabled child through prenatal diagnosis."). Botkin also notes, however, that distinctions may be made between those disabled from genetic conditions that can be detected prenatally and the disabled who have limitations from other causes, such as injury, stroke, or infection. *Id*. Because PGD can select genetic characteristics of future children, it could promote societal expectations of perfect children, thus creating a more narrow intolerance of those disabled due to genetic conditions and possibly of the parents who choose to have such a child. *Id*.

48. Roberts, *supra* note 23, at 10.

> 'Pro-Life': The embryo-fetus has full moral status, equal to that of any adult human, from the moment of conception; or
>
> 'Pro-Choice': The embryo-fetus has no intrinsic moral status . . . . Such status is only acquired at birth or even beyond and, when acquired, is acquired to the full extent possible. Until then, any moral status the embryo-fetus has is derived indirectly from the moral status of those with intrinsic moral status; or
>
> 'Compromise': The embryo-fetus has, to begin with, a minimal intrinsic moral status, which increases with its development during gestation. Full moral status is, however, achieved only at birth or beyond.[49]

Under the "pro-life view," there is no distinction between discarding an embryo and aborting a fetus, as both are morally unacceptable.[50] Strict proponents of the pro-life view may actually find PGD *more* ethically troubling and problematic than traditional prenatal diagnosis because PGD creates numerous embryos and thus the loss of prenatal life can be greater than if couples had opted for traditional prenatal diagnosis and selective termination of pregnancy.[51] Under the "pro-choice view," fetuses and embryos are "equal in their lack of significant moral standing."[52] Commentators who adopt the "compromise view" disagree over whether development is a seamless continuum, with the moral status increasing incrementally with development, or if moral status is based on the achievement of milestones in the developmental process that have particular moral significance.[53]

Advocates for PGD emphasize that the preliminary screening reduces the number of abortions, a procedure that carries "greater medical and emotional consequences."[54] They argue that much of society adopts the view that the fetus has greater moral standing than does the preimplantation embryo.[55] The

49. Deryck Beyleveld, *The Moral Status of the Human Embryo and Fetus*, *in* THE ETHICS OF GENETICS IN HUMAN PROCREATION 59 (Hille Haker & Deryck Beyleveld eds., 2000) (applying the moral theory of Alan Gewirth in ALAN GEWIRTH, REASON AND MORALITY (1978)). Beyleveld notes that these views are "extreme positions" and that the use of these labels in public discourse may not be as uncompromising. Beyleveld, *supra*, at 78 n.2.

50. Botkin, *supra* note 27, at 20; *see also* Draper & Chadwick, *supra* note 24, at 114–15. "[M]orally significant human life begins at conception." *Id*. at 114. This view might prevent the embryo from being implanted or allow termination of a pregnancy if it was shown that it was in its best interests, provided that its life is not worth living. *Id*. at 115.

51. Botkin, *supra* note 27, at 21.

52. *Id*. at 20; *see also* Draper & Chadwick, *supra* note 24, at 114 (noting that many view failing to implant an embryo as morally preferable to killing a more fully developed fetus). They believe that the embryo acquires greater moral status as it develops toward viability. *Id.*

53. Botkin, *supra* note 27, at 20. Botkin notes that the developmental milestones include "formation of the primitive streak at 14 days, 'quickening' at about 18 weeks, development of 'brain life' at about 20 to 22 weeks, a sapient or sentient state emerging at about 22 to 24 weeks, and viability at 23 to 24 weeks of gestation." *Id*. at 20–21.

54. Roberts, *supra* note 23, at 10.

55. Botkin, *supra* note 27, at 21.

wide acceptance of this view means that a couple's preference of discarding an embryo rather than terminating a fetus is ethically justified.[56]

3. Fear That Access to the Technology Will Be Limited

PGD also raises concerns about access to the technology. The substantial cost of PGD is not affordable for most couples, and insurance and government programs are not likely to cover the costs of PGD because other existing methods of prenatal diagnosis are less expensive.[57] If PGD were to become commercially available on a broad scale, it would likely be used almost exclusively by wealthy couples.[58] There is a discrepancy between urban white women versus rural and other women in the United States in the use of prenatal diagnosis.[59] Some fear that a social divide will be created where the rich suffer from fewer genetic diseases than the poor.[60] There is also speculation that insurance companies may someday offer discounts to families who do use PGD and will penalize families who do not use it.[61]

56. *Id*.

57. *Id*. at 25; *see also A Discussion of Challenges*, *supra* note 36, at 22 (estimating that the cost of the procedure is $12,500–16,000); Steinbock, *supra* note 9, at 177 (recognizing no data yet as to the specific cost of PGD, but each cycle of IVF can cost between $5,000–7,000, which is often not covered by insurance).

58. Botkin, *supra* note 27, at 25; *see also* FUKUYAMA, *supra* note 18, at 80 ("Designer babies will be expensive at first and an option only for the well-to-do. Whether having a designer baby will ever become cheap and relatively popular will depend on how rapidly technologies like preimplantation diagnosis come down the cost curve."); Maxwell J. Mehlman & Kirsten M. Rabe, *Any DNA to Declare? Regulating Offshore Access to Genetic Enhancement*, 28 AM. J.L. & MED. 179, 181–82 (2002) (making a similar observation with active genetic enhancement by noting that couples who can afford such technology are wealthier individuals who "already possess social advantages such as money, status and access to information concerning new biotechnologies" and that such technology "may inadvertently widen the gap between the rich and the poor").

59. Botkin, *supra* note 27, at 25 (noting that this discrepancy represents financial and cultural differences).

60. Knox, *supra* note 46, at 443.

61. *Id*.; *see also* Michael J. Malinowski, *Choosing the Genetic Makeup of Children: Our Eugenics Past-Present, and Future?*, 36 CONN. L. REV. 125, 207 (2003).

> When the price of PGD drops low enough to make the technology standard care—and the pace of advancement of bioinformatics suggests it will and perhaps more quickly than many estimate—will the pressure to have a baby as healthy and desirable as medically possible actually compel prospective parents to use PGD even beyond their levels of comfort—meaning, ironically, could PGD become an imposition and reduce the freedom of parents to choose?

Id.

C. Questions Surrounding the Therapeutic Uses of PGD

Although controversial, using PGD to avoid serious and early-onset illness in future children is widely accepted.[62] As noted in the introduction, however, couples have begun to use PGD for therapeutic purposes that are even more controversial. These uses will be further discussed in the following sections.

1. PGD Used for Late-Onset Disorders

A more controversial use of PGD is testing for mere susceptibility to disease and for late-onset disorders, such as Huntington's disease.[63] Recently, a woman who carried the gene for early onset Alzheimer's used PGD to ensure that her daughter would not similarly suffer from the disease.[64] The American doctors released news of their work when they were sure that the child did not inherit the tendency to develop early onset Alzheimer's.[65]

Patients' groups and ethicists protest such use of PGD because it rejects embryos simply because the babies would have a chance at developing a disease in middle age.[66] They argue that the children are not born with an illness—just a predisposition—and to claim that their lives are not worth living is morally questionable.[67] Advocates for PGD argue that the costs of rearing a child with a late-onset disease can be emotionally and financially significant and may be the basis of the couple's decision whether to reproduce at all.[68]

62. Wolf et al., *supra* note 4, at 327.

63. *Id.*

64. Nigel Hawkes, *Screening Frees Baby from Mother's Alzheimer Gene*, THE TIMES OF LONDON, Feb. 27, 2002, at 1, *available at* 2002 WL 4185158. *But see* Steinbock, *supra* note 9, at 187 (noting that, at this time, there is no prenatal test for Alzheimer's). The APOE genotype has been discovered to be the single most important genetic determinant of susceptibility to Alzheimer's, but some individuals who have the genotype do not develop the disease and others with a different genotype do develop it. *Id.* Alzheimer's is also a multifactorial disease, meaning it is affected by both environmental and genetic factors. *Id.* A reliable test may never be likely, but PGD may help reduce the risk. For more discussion as to whether PGD should be used to avoid inheritance of early Alzheimer's, see *Should Preimplantation Genetic Diagnosis Be Used to Avoid Inheritance of Early Alzheimer's Disease*, FAMILY PRACTICE NEWS, Sept. 15, 2002, at 9. For further discussion about this first experience of using PGD for early-onset Alzheimer's, see Yury Verlinsky et al., *Preimplantation Diagnosis for Early-Onset Alzheimer Disease Caused by V717L Mutation*, 287 JAMA 1018 (2002); Dena Towner & Roberta Springer Loewy, *Ethics of Preimplantation Genetic Diagnosis for a Woman Destined to Develop Early-Onset Alzheimer Disease*, 287 JAMA 1038 (2002).

65. James Chapman, *The Test-Tube Girl Who Will Never Get Alzheimer's*, DAILY MAIL (London), Feb. 27, 2002, at 6, *available at* 2002 WL 14481702.

66. *Id.*; *see also* M. Spriggs, *Genetically Selected Baby Free of Inherited Predisposition to Early-Onset Alzheimer's Disease*, 28 J. MED. ETHICS 290, 290 (2002) (stating that this use of PGD is more controversial because "an embryo is being rejected on the basis that it may develop a disease in middle age").

67. Chapman, *supra* note 65.

68. Roberts, *supra* note 23, at 12.

2. PGD Used to Create a "Saviour Sibling"

A more controversial but increasingly common use of PGD is to create a donor child whose tissue matches with a preexisting sibling in need of a stem cell transplant.[69] This is how the Nash family used PGD, as described in the first scenario. Creating a donor child to save a sick sibling actually involves three technologies: IVF, PGD for tissue matching, and stem cell transplant.[70] Although there have been many documented success stories, data that demonstrates the efficacy of combining the technologies for saving or prolonging the child's life is lacking.[71] Similarly, no data examines the medical and psychosocial risks for both the donor and recipient child.[72]

Some commentators have criticized families like the Nashes for choosing to use PGD to create a child for donor purposes and call this an unethical reason to have children and an immoral objectification of the donor child.[73] The main ethical argument against such a use is the alleged instrumentalization of the donor child: the donor child becomes an instrument to cure another child.[74] It can be difficult to determine when an act instrumentalizes a person.[75] The donor child, however, may not be instrumentalized at all

69. Wolf et al., *supra* note 4, at 327. The United States has no existing guidelines on the proper use of PGD to create a stem cell donor; the only countries believed to have done so are England and Australia. *Id*. at 329. This Comment summarizes the scope of the issue and offers recommendations as to when using PGD to create a donor child is ethical; *see also* R. Ashcroft, *Bach to the Future: Response to: Extending Preimplantation Genetic Diagnosis: Medical and Non-medical Uses*, 29 J. MED. ETHICS 217, 217 (2003) (noting that "the question is whether something which is not positively *in* a child's interest can be tolerated or permitted if it is not positively *against* the child's interests"); *see e.g.*, M. Spriggs & J. Savulescu, *"Saviour Siblings"*, 28 J. MED. ETHICS 289, 289 (2002) (showing how the news media and literature has referred to this trend as the creation of "saviour siblings").

70. Wolf et al., *supra* note 4, at 327.

71. *Id*.

72. *Id*.

73. *See* Stephanie J. Hong, Note, *And "Cloning" Makes Three: A Constitutional Comparison Between Cloning and Other Assisted Reproductive Technologies*, 26 HASTINGS CONST. L.Q. 741, 780 (1999) (noting the presence of "commodification-objectification concerns in creating a child simply to produce an organ or tissue donor").

74. G. Pennings et al., *Ethical Considerations on Preimplantation Genetic Diagnosis for HLA Typing to Match a Future Child as a Donor of Haematopoietic Stem Cells to a Sibling*, 17 HUM. REPROD. 534, 536 (2002) (noting that it is "generally agreed that using someone as a means is not unethical" and "[a]n action should only be condemned when it treats a person *solely* as a means"), *available at* http://humrep.oupjournals.org/cgi/content/full/17/3/534.

75. *Id*. (giving parents who decide to have another child as a companion and a playmate for the first one as an example and asking whether this second child should be considered an instrument). *But see* Wolf et al., *supra* note 4, at 330 (stating that "[c]ommentators thus far have found the practice ethically acceptable as long as the parents intend to rear and love the donor child").

because it is arguably unlikely that parents who take such steps to save the recipient child will not treat the donor child as an equal to the existing child.[76]

Similarly, advocates for PGD counter that it may be *more* unethical not to use PGD if it could potentially save the life of an ill child. Dr. Charles Strom, director of medical genetics at the Illinois Masonic Medical Center (where the Nash family used PGD), dismisses the argument that there are "good" or "bad" reasons to have a child.[77] He stated, "People have kids for all kinds of reasons: to save a failing marriage, to work on the family farm, to perpetuate the family name. In the scheme of things, [Adam] is the most wanted child I've ever met. They love the heck out of this kid."[78]

Opponents of PGD argue that a heavy burden is placed on the donor child: if the transplant fails, the child may experience feelings of unworthiness, deficiency, and inability to achieve expectations.[79] They also believe that the donor child may feel hurt when he learns why he was born.[80] Advocates counter that the donor child is too young to understand what is happening at the time, and when he is eventually able to understand his role in the events, the psychosocial effects will be more diluted and he may agree with the decision his parents have made.[81] Learning that one was conceived to save a sibling might also increase self-esteem and self-worth.[82] Finally, when the treatment is possible with umbilical cord stem cells, no real risk, harm, or pain is imposed on the donor child.[83]

76. *See* Mark P. Aulisio et al., *Procreation for Donation: The Moral and Political Permissibility of "Having a Child to Save a Child,"* 10 CAMBRIDGE Q. OF HEALTHCARE ETHICS 408, 415 (2001) (noting that "it seems reasonable to assume that parents who care enough about an existing child to bring another child into existence partly in the hopes of saving the existing child are likely to love and care for their new child as well"); *see also* J.A. Robertson, *Extending Preimplantation Genetic Diagnosis: Medical and Non-Medical Uses*, 29 J. MED. ETHICS 213, 214 (2003) (suggesting that parents will value the new child for its own sake, not only for the stem cells it produced).

77. Weiss, *supra* note 5, at A14; *see also* Aulisio et al., *supra* note 76, at 414 (noting that "[a]lthough having a child to provide matching organs or tissue may be less than optimal, having children for certain other reasons, or no reason at all, is also less than optimal").

78. Weiss, *supra* note 5, at A14; *see also* Aulisio et al., *supra* note 76, at 414 (suggesting that having a child to save a child is a better reason to have a child than any other reason and that procreation is not limited to those other reasons).

79. Pennings et al., *supra* note 74, at 537.

80. *Id*.

81. *Id*. at 537–38.

82. *Id*. at 537.

83. *Id*. (noting that the donation of a kidney would be a more difficult decision. The subsequent use of stem cells is not against the interest of the donor child.).

D. Questions Surrounding Non-therapeutic Uses of PGD

In general, there is public support for prenatal diagnosis for "serious" genetic conditions.[84] There is also a general belief that prenatal diagnosis for more minor conditions is ethically troubling, but such use is often permitted based on a respect for parental autonomy in reproductive matters.[85] The most controversial uses of PGD are for those purposes that are not medical at all.[86] Such non-therapeutic uses of PGD include screening for cosmetic traits, performance traits, and gender/sex traits.[87] This is troubling to some ethicists who wonder how to distinguish among reasons for wanting to create a certain child.[88] There is a conflict in social values between "reluctance to validate termination of a fetus for a less than serious medical condition and a desire to respect parental autonomy."[89]

1. PGD Used for Cosmetic Traits

The value conflict will continue to escalate as the number of conditions that can be detected by PGD rises.[90] Because PGD does not involve abortion, parents may feel social pressure to avoid genetic disorders in their offspring and undergo testing.[91] Parents who can afford PGD may use it to become increasingly selective about traits for less life-threatening reasons, which could

84. *See* Steinbock, *supra* note 9, at 179 (noting that such "serious" conditions include Tay-Sachs disease, spina bifida, cystic fibrosis, sickle cell disease, hemophilia, and muscular dystrophy); *see also* Genetics and Public Policy Center, Berman Bioethics Institute, John Hopkins University, *Attitudes About Reproductive Genetics* (2002), *at* http://www.dnapolicy.org/research/reproductiveGenetics.jhtml [hereinafter *Attitudes About Reproductive Genetics*]. The survey results of a random sampling of 1,211 Americans were published in December 2002. *Id*. Two-thirds of the respondents approved of using reproductive technologies to help parents have a baby free of a serious genetic disease. *Id*. The greatest benefits of such technologies are the ability "to wipe out certain genetic diseases forever" (41 percent) and to improve the chances that the baby will be healthy (27 percent). *Id*.

85. Botkin, *supra* note 27, at 21.

86. Ashcroft, *supra* note 69, at 217; *see also Attitudes About Reproductive Genetics*, *supra* note 84 (noting that over seventy percent of the respondents disapproved of using the technologies to identify or select traits such as strength or intelligence).

87. Knox, *supra* note 46, at 447.

88. Peter Gorner, *Embryo Is Picked to Try to Save Sister's Life*, CHI. TRIB., Oct. 2, 2000, at 1.

89. Botkin, *supra* note 27, at 21.

90. *Id*.; *see also* Robertson, *supra* note 76, at 214 (stating that many predict that PGD will eventually be used to select traits such as intelligence, height, sexual orientation, beauty, hair and eye color, and memory).

91. King, *supra* note 41, at 179–80 (noting that women who refuse prenatal testing because they cannot kill their child-to-be receive public sympathy, but it is less likely that there will be that sympathy for parents who reject the opportunity of PGD merely on the grounds of wanting to leave things to chance); *see also* Botkin, *supra* note 27, at 23. "Widespread use [of PGD] could significantly reduce societal tolerance for 'less than perfect' babies." *Id*.

lead children to higher levels of perfection.[92] When multiple embryos are screened, there is an inherent pressure to select the most desirable traits; therefore, PGD has great eugenic potential.[93] Opponents of PGD believe that the availability of several embryos means that the threshold for selection is lowered, and thus the slide down the slippery slope has begun.[94] As Art Caplan, a leading ethicist, comments, "[W]hen you design children for purposes that are acceptable, where do you draw the line? Blue eyes? A kidney? A testacle? [sic] Pre-implantation genetics opens the door to those kinds of questions."[95] The phrase "designer children" is often used to describe children whose parents have used genetic technology in their creation.[96] Opponents assume, and morally condemn, the possibility that parents will "design their children because they are more concerned with fashion and pleasing themselves than with valuing the children for the children's own sake."[97]

Although it is not currently possible to screen for most behavioral and physical traits,[98] selection of traits for cosmetic purposes has been compared to racial discrimination.[99] Parents who want to use PGD for this purpose should be counseled that the procedure can fail, that a child may later opt to change

92. *See generally* Gorner, *supra* note 88; *see also* Botkin, *supra* note 27, at 22. ("[S]ome couples may pursue PGD for no other reason than to select their ideal embryo. This could well be a growth industry in the coming century for couples who can afford it.").

93. *See* King, *supra* note 41, at 180 (stating that PGD allow parents to "adopt a far more pro-active, directing role, choosing their children in a way which is not so far removed from their experience as consumers, choosing amongst different products." King refers to this as "consumer eugenics."); *see also* DIANE B. PAUL, CONTROLLING HUMAN HEREDITY: 1865 TO THE PRESENT 133 (1995) (observing that "some have argued that eugenics is being revived by our increased ability to choose the kind of children we want").

94. Pennings et al., *supra* note 74, at 536. Opponents believe that the slippery slope is more prevalent for PGD than for other forms of prenatal diagnosis because there is no restrictive barrier like an abortion. *Id*. The moral and psychological influences of a possible abortion following other types of prenatal diagnosis function as a barrier to prevent diagnosis for "trivial" reasons. *Id*.

95. Gorner, *supra* note 88, at 1.

96. Donrich W. Jordaan, *Preimplantation Genetic Screening and Selection: An Ethical Analysis*, 22 BIOTECHNOLOGY L. REP. 586, 589 (2003).

97. *Id*. (stating that the argument is that such technology is unethical because it leads to the instrumentalization of children).

98. Roberts, *supra* note 23, at 31; *see also* Robertson, *supra* note 76, at 214 (suggesting that it is still useful to consider "whether the proposed use serves valid reproductive or rearing interests; whether those interests are sufficient to justify creating and destroying embryos; whether selecting for a trait will harm resulting children; whether it will stigmatise [sic] existing persons, and whether it will create other social harms").

99. Knox, *supra* note 46, at 447. "If it is both morally and legally objectionable to discriminate against someone due to skin color, it may be just as unacceptable to discriminate against someone based on superficial traits like hair and eye color." *Id*. at 448.

his appearance, and that unrealistic behavior expectations should not be placed on children selected for desired physical traits.[100]

2. PGD Used for Performance Traits

Parents may also desire to use PGD to produce children with certain performance traits, such as musical talent or pitch and intelligence. The selection of embryos with certain genes believed to represent favorable or superior genetic traits has not yet been widely practiced in the United States, but is likely to be used as the knowledge base of genetics expands.[101] The strongest case for the parents to use the technology this way is if they can persuasively assert that they would not reproduce at all unless they could select that trait, and if they have a plausible explanation for that view.[102] Parents can try to instill that trait after birth; therefore, they arguably might have that right before birth as well.[103] To prevent the possibility that the future children will be exploited, these parents should again be counseled that children have a variety of influences exerted upon them and that they could develop other passions and talents. Commentators speculate how using PGD to screen for non-medical conditions could potentially affect the parent–child relationship.[104] Traditionally, parents have had hopes and expectations for their children, but have had little control—what would happen if parents had very specific expectations based on their experiences in prenatal testing and selection?[105] There is speculation that children could feel that the essence of themselves no longer belongs to them because their parents oversaw it.[106] Parents may also put too much pressure on these selected children, which

100. *Id*.

101. Bruce L. Wilder, *Assisted Reproduction Technology: Trends and Suggestions for the Developing Law*, 18 J. AM. ACAD. MATRIMONIAL LAW. 177, 204 (2002). This is especially likely if no regulatory body is established.

102. Robertson, *supra* note 76, at 215 (suggesting that preferring the trait of perfect pitch might be extremely important and understandable in highly musical families).

103. *Id*.

104. Botkin, *supra* note 27, at 23; King, *supra* note 41, at 180 (suggesting that selection of the "best" embryo creates a new relationship between parents and offspring).

105. Botkin, *supra* note 27, at 23.

106. King, *supra* note 41, at 180. The author notes what Kahn has stated in reference to cloning:

> Part of the individuality and dignity of a person probably lies in the uniqueness and unpredictability surrounding his or her development. As a result, the uncertainty of the great lottery of heredity constitutes the principal protection for human beings against biological predetermination imposed by third parties, including parents. One of the blessings of the relationship between parents and their children is their inevitable difference, which results in parents loving their children for what they are, rather than endeavouring to make them what they want.

Id.

could cause them to suffer psychological or self-esteem issues.[107] Many of the traits that parents might potentially choose would make children more *competitive* in society, but success in competition and actual *contentment* may be dramatically different.[108]

Using PGD to screen for non-medical traits could cause further division between the wealthy and the poor as noted in the previous section.[109] The poor will face further disadvantages because they cannot afford the procedure.[110] Selection of embryos based on intelligence, physical, or psychological traits would contribute to inequality in society by circumventing the natural random process of evolution.[111] Bioethicist George Annas stated:

> [t]o try to give your child a genetic head start would, I think, be irresistible for parents who could afford to pay for it. . . . This could be very problematic for society. It's a road I don't think we should go down. But it's one I could see us going down very quickly as a result of advertising, peer pressure, and so on . . . and that parents who don't "take advantage" of the new genetics will soon be seen as bad or even neglectful parents.[112]

3. PGD Used for Sex Selection

Finally, selection of children based on gender/sex traits is the most controversial use of PGD, as the plight of the potential parents generates little public sympathy.[113] Because sex selection is now feasible, interest in it is "exploding."[114] Other countries such as India and China have long valued producing a baby boy and have practiced infanticide, where infants are suffocated shortly after birth, or have used selective abortions to terminate

107. Knox, *supra* note 46, at 449.

108. Botkin, *supra* note 27, at 24 (stating that "[t]here is less moral force to the claim that parents should be supported in their efforts to gain competitive advantage for their children, particularly when competitive advantage remains possible through traditional means such as education, wealth, and hard work").

109. *See supra* Part II.B.3.

110. *See* Knox, *supra* note 46, at 449. *But see* Botkin, *supra* note 27, at 25 (noting that affluent couples would be most apt to use PGD if it became commercially available; however, less affluent infertile couples who have their IVF costs covered by insurance may be able to use PGD if they could pay the additional marginal costs of genetic analysis).

111. Roberts, *supra* note 23, at 35.

112. *Id*.; *see also* King, *supra* note 41, at 181. "Clearly, there is likely to be a tendency for parents to select offspring which conform best to social norms, with regard to health and physical ability, appearance and aptitudes." *Id*.

113. Ashcroft, *supra* note 69, at 217; *see also* Wilder, *supra* note 101, at 204 (suggesting that the practice is controversial because it involves the destruction of an otherwise (presumably) normal embryo).

114. Claudia Kalb, *Brave New Babies*, NEWSWEEK, Jan. 26, 2004, at 46 (noting the emergence of such web sites as http://www.choosethesexofyourbaby.com and http://www.myboyorgirl.com). The web site for the Fertility Institutes in Los Angeles, which performs sex selection with PGD, has received 85,000 hits in the last six months. *Id.*

female fetuses.[115] Potential parents in the United States have already begun to use PGD to select embryos on the basis of sex.[116] For example, a California woman with three sons used PGD in 2002 to select a girl because she wanted to recreate the positive relationship she had with her own mother.[117] Such stories are becoming more common, and increasing numbers of individuals, geneticists, and physicians believe that people are entitled to sex selection if they request it.[118]

Sex selection has sparked debate over whether parents' procreative freedom to choose their child's gender outweighs society's greater concern regarding gender stereotypes and equality.[119] Parents who desire sex selection state that they want a balanced family, meaning that their family has children of one sex and they want their last child to be of the opposite sex.[120] But, to date, there is no evidence demonstrating that the need or desire for gender variety is important or whether many couples would refrain from having another child if PGD for sex selection was not possible.[121]

One argument against this use of PGD is that sex selection will lead to a changed sex ratio, with fewer women than men, thus leading to inequality for women.[122] Some fertility specialists have even referred to sex selection as sex

115. *See* Roberts, *supra* note 23, at 14–15. Families value baby boys for continued lineage and economic survival of the family. *Id.* at 14; *see also* Kalb, *supra* note 114, at 46 (noting that "[t]hroughout history, humans have wished for a child of one sex or the other and have been willing to do just about anything to get it").

116. *See* Gina Kolata, *Fertility Ethics Authority Approves Sex Selection*, N.Y. TIMES, Sept. 28, 2001, at A16 (noting that fertility specialist Dr. Norbert Gleicher stated that "we have a list of patients who asked for it."). Parents in Australia are also using PGD for sex selection. *See infra* Part III.C.

117. Aaron Zitner, *A Girl or a Boy, You Pick*, L.A. TIMES, July 23, 2002, at A1, A13. This is often described as "family balancing." *See also* David McCarthy, *Why Sex Selection Should Be Legal*, 27 J. MED. ETHICS 302, 303 (2001) (noting that couples will go to great efforts to select the sex of their child because they want to have a balanced family). Other American families have used PGD for sex selection. *See generally* Kalb, *supra* note 114, at 44 (describing American families who have used PGD, or another technology, for sex selection).

118. Kelly M. Plummer, Comment, *Ending Parents' Unlimited Power to Choose: Legislation is Necessary to Prohibit Parents' Selection of Their Children's Sex and Characteristics*, 47 ST. LOUIS U. L.J. 517, 523 (2003). *But see* Kalb, *supra* note 114, at 49–50 (noting that leading PGD authority Mark Hughes stated, "[G]ender [is not] a disease. There is no illness, no suffering and no reason for a physician to be involved. Besides, we're too busy helping desperate couples with serious disease build healthy families.").

119. See *infra* Part IV for a discussion on the scope of procreative liberty.

120. McCarthy, *supra* note 117, at 303. *But see* Kalb, *supra* note 114, at 50 (quoting Dr. Mark Sauer of Columbia who "balks" at the idea of family balance. He stated, "What are you balancing? It discredits the value of an individual life." He refuses to perform PGD solely for sex selection.).

121. Robertson, *supra* note 76, at 215.

122. McCarthy, *supra* note 117, at 305; *see also* Robertson, *supra* note 76, at 214. "The use of medical technology to select the sex of offspring is highly controversial because of the bias

discrimination.[123] It is speculated that selection for a first child would favor males, which if executed on a large scale could lead to great disparities in the sex ratio of the population.[124] This may only slightly contribute to societal sex ratio imbalances, but its use is apt to reflect cultural notions of male privilege and could reinforce sexism toward women.[125]

Those who support using PGD for sex selection argue that allowing families to select embryos of the desired sex will maintain population control, gender balancing within the family, a desire for parental companionship by raising a child of the same gender, and a preferred gender order among one's children.[126] In addition to the supposed threat to the sex ratio, opponents to this use of PGD also worry that it will only be available to those who can afford it.[127] Leading ethicist Leon Kass, chair of the President's Council on Bioethics, believes that "[c]hildren are going to hold their parents responsible for having made them this way."[128]

The ASRM has not offered consistent guidance on the issue of sex selection. In 1999, the Ethics Committee of the ASRM ("the Committee") reviewed sex selection for solely nonmedical reasons.[129] The ASRM first

against females which it usually reflects or expresses, and the resulting social disruptions which it might cause." *Id.*

123. Kolata, *supra* note 116, at A16 (quoting Dr James Grifo, president-elect of the Society for Assisted Reproductive Technology, who stated, "Sex selection is sex discrimination, and I don't think that is ethical. . . . It's not ethical to take someone off the street and help them have a boy or a girl." Dr. William Schoolcraft of the Colorado Center for Reproductive Medicine asked, "What's the next step? . . . As we learn more about genetics, do we reject kids who do not have superior intelligence or who don't have the right color hair and eyes? . . . We have a responsibility to be conservative and cautious. . . . It's our responsibility not to misuse these technologies."). *See* Zitner, *supra* note 117, at A12 (stating that Dr. Robert E. Anderson of the Southern California Center for Reproductive Medicine in Newport Beach finds rejecting a boy or girl when there is no medical need is "[m]orally reprehensible" and that "[m]ost Americans, no matter where they come down on the question of where life begins, would find something morally objectionable about creating embryos and then discarding some simply because of their sex."); *see also* Kalb, *supra* note 114, at 47 (speculating whether choosing one gender over another could become this century's form of sex discrimination).

124. Robertson, *supra* note 76, at 214. *But see* McCarthy, *supra* note 117, at 305 (suggesting that if there were fewer women, they might be more valued and concluding overall that "the threat to the sex ratio is far from clear").

125. Robertson, *supra* note 76, at 214 (also noting that using PGD for family balancing is less likely to be susceptible to charges of sexism).

126. *See* Ethics Comm. of the Am. Soc'y for Reprod. Med., *Sex Selection and Preimplantation Genetic Diagnosis*, 72 FERTILITY & STERILITY 595, 596 (1999), *available at* http://www.asrm.org/Media/Ethics/Sex_Selection.pdf [hereinafter Ethics Comm., *Sex Selection and Preimplantation Genetic Diagnosis*].

127. McCarthy, *supra* note 117, at 305; *see supra* Part II.B.3.

128. Kalb, *supra* note 114, at 51.

129. *See generally* Ethics Comm., *Sex Selection and Preimplantation Genetic Diagnosis*, *supra* note 126, at 598.

noted that it is ethically acceptable to use PGD for sex selection to prevent the transmission of serious genetic diseases.[130] The ASRM then recommended that, for patients undergoing IVF, PGD used for sex selection for nonmedical reasons *should not be encouraged*.[131] The Committee finally concluded that the initiation of IVF with PGD solely for sex selection "holds even greater risk of unwarranted gender bias, social harm, and the diversion of medical resources from genuine medical need. It therefore should be *discouraged*."[132]

In 2001, however, the acting head of the Committee, John Robertson, issued a letter in response to a doctor's request for clarification of the ASRM's position, believing that this letter reflected the position of the entire Committee.[133] In this letter, Robertson stated that it is sometimes acceptable for couples to choose the sex of their children by picking an embryo of the desired gender and discarding the rest.[134] He stated that "gender variety" was one acceptable use of this sex selection technique.[135] Robertson believed that gender variety could be offered "when there is a good reason to think that the couple is fully informed of the risks of the procedure and are counseled about having unrealistic expectations about the behavior of children of the preferred gender."[136] Physicians thus could offer PGD for sex selection under certain conditions.[137]

130. *Id*. (recognizing that such use "is not inherently gender biased, bears little risk of consequences detrimental to individuals or to society, and represents a use of medical resources for reasons of human health").

131. *Id*. (noting that there is "some risk of gender bias, harm to individuals and society, and inappropriateness in the use and allocation of limited medical resources").

132. *Id*. (emphasis added).

133. Kolata, *supra* note 116, at A16.

134. *Id*.

135. *Id*. (meaning that a couple who had a child of one sex could ethically choose embryos to guarantee the embryo selected was of the opposite sex).

136. *Id*.

137. *Id*. The doctor's request, and Robertson's response, sprang out of the Committee's 2001 finding that preconception gender selection methods like sperm sorting *could* be used for gender variety. *Id*. In this 2001 report, the Committee stated that couples seeking gender variety in their offspring can be offered preconception gender selection if they:

> [1] are fully informed of the risks of failure, [2] affirm that they will fully accept children of the opposite sex if the preconception gender selection fails, [3] are counseled about having unrealistic expectations about the behavior of children of the preferred gender, and [4] are offered the opportunity to participate in research to track and assess the safety, efficacy, and demographics of preconception selection.

Ethics Comm. of the Am. Soc'y for Reprod. Med., *Preconception Gender Selection for Nonmedical Reasons*, 75 FERTILITY & STERILITY 861, 863–64 (2001), *available at* http://www.asrm.org/Media/Ethics/preconceptiongender.pdf (last visited Nov. 3, 2004). The Committee also noted that "[p]ractitioners offering assisted reproductive services are under no legal or ethical obligation to provide nonmedically indicated preconception methods of gender selection." *Id.* at 864.

In the spring of 2002, the Committee revised Robertson's controversial opinion, and the practice of using PGD for the first child or for gender variety was once again discouraged.[138] The new Committee report (again penned by Robertson) concluded that sperm sorting and PGD were different, because the former does not involve the creation and destruction of embryos.[139] As Robertson explained, the Committee felt that because embryos have the potential to implant and bring forth a new person, they deserve "special respect" and "the interest in choosing the gender of offspring had not yet been shown to be strong enough to justify the creation and destruction of embryos solely for gender variety in a family."[140]

III. INTERNATIONAL REGULATION OF PGD

To date, the United States has created virtually no federal regulation regarding PGD, but other countries have taken a more definitive stance and have exerted some control over PGD, or, alternatively, have outlawed it all together. PGD is banned in Austria, Germany, Ireland, and Switzerland.[141] Its use is limited by legislation in France, Spain, Sweden, and the United Kingdom.[142] Belgium, Israel, the Netherlands, Italy, Greece, and the United Kingdom control PGD by a national oversight agency.[143] This section will more closely examine how some of these countries have responded to the development of PGD and other ARTs.

138. John Robertson, *Sex Selection: Final Word from the ASRM Ethics Committee on the Use of PGD*, HASTINGS CTR. REP., Mar.–Apr. 2002, at 6, 6; *see also* Gina Kolata, *Fertility Society Opposes Choosing Embryos Just for Sex Selection*, N.Y. TIMES, Feb. 16, 2002, at A16. A chain of fertility centers said it would immediately abide by the decision. *Id.*

139. Robertson, *supra* note 138, at 6.

140. *Id*.

141. Melissa Healy, *Fertility's New Frontier*, L.A. TIMES, July 21, 2003, at F8. *See generally* John Harris, *Stem Cells, Sex, and Procreation*, 12 CAMBRIDGE Q. OF HEALTHCARE ETHICS 353, 356–60 (2003) (discussing which European countries conduct embryo research). Germany and Austria ban all embryo research. *Id*. at 358.

142. *See* Healy, *supra* note 141, at F8. *See generally* Harris, *supra* note 141, at 358 (discussing which European countries conduct embryo research). France "allows 'the study of embryos without prejudicing their integrity' and preimplantation diagnosis." *Id*. Spain offers protection to the in vitro viable embryo, and it permits embryo research under specified conditions. *Id*. Finland and Spain also permit embryo research under specified conditions, while the United Kingdom has the most liberal research conditions. *Id*.

143. *See* Healy, *supra* note 141, at F1. *See generally* Harris, *supra* note 141, at 358 (noting that for embryo research, Italy and Greece rely on the stipulated conditions of the Council of Europe's Convention of Human Rights and Biomedicine).

A. England

The use of PGD is authorized on a case-by-case basis, as outlined in the Human Fertilisation and Embryology Act of 1990.[144] The Act also created the Human Fertilisation and Embryology Authority ("HFEA"), which licenses and regulates the use of PGD and generally regulates clinics offering assisted reproductive procedures.[145] The HFEA defines the limits of where research and treatment may venture and assures public representation by requiring that half of its members be specialists in areas outside of medicine and research.[146] The HFEA has established training and assessment criteria for laboratories and individuals carrying out the embryo biopsy part of the PGD procedure, and clinics cannot perform any other tests or treat individuals for new disorders without approval.[147] By March 15, 2004, PGD was available at ten fertility clinics in England.[148]

The English media has extensively debated and discussed the different uses of PGD. Unlike the United States, PGD can be used to determine gender in England only when there is a need to avoid a serious genetic condition.[149] This ban was challenged in 2000 by a Scottish family who wanted to use PGD to conceive a girl after the death of their only daughter, but no fertility clincs

144. *See* Human Fertilisation and Embryology Act, 1990, c. 37 (Eng.); *see also* John McMillan, *Sex Selection in the United Kingdom*, HASTINGS CTR. REP. Jan.–Feb. 2002, at 28, 29. McMillan describes the Act as follows:

> The act divides treatments involving human gametes and embryos into three categories. First, there are treatments that are illegal. Second, there are treatments that are illegal unless carried out by a licensed clinic. . . . [These] include the creation of embryos in vitro, keeping embryos or gametes, placing any embryo into a woman, and, crucially, practices as may be specified in or determined in regulations. Finally, there are those treatments that are not covered by the act and can lawfully be carried out without a license. Examples of such treatment include artificial insemination using the husband's sperm, and gamete intra fallopian transfer.

Id. (citations omitted).

145. *See* Human Fertilisation and Embryology Act, 1990, c. 37 (Eng.), *supra* note 144, at § 8 (describing the general functions of the HFEA); McMillan, *supra* note 144, at 29 (noting that the HFEA publishes a code of practice for licensed clinics and also inspects these clinics to see that the standards are met); Roberts, *supra* note 23, 46.

146. Roberts, *supra* note 23, at 46.

147. *See* Human Fertilisation and Embryology Act, *supra* note 144, at §§ 9–10 (describing the HFEA's licensing committees and licensing procedure); *see also* Roberts, *supra* note 23, at 29.

148. Dr. Jess Buxton, *Embryo Screening (PGD)*, *at* http://www.bionews.org.uk/update.lasso?storyid=1639 (last updated March 15, 2004).

149. Human Fertilisation and Embryology Authority, Revised Code of Practice, Sixth Ed., § 8.9 (2003) (stating that "[t]reatment centres are expected not to . . . [s]elect the sex of embryos for social reasons"). *See* McMillan, *supra* note 144, at 29. Creating embryos for IVF is legal only when it is performed by a licensed clinic in accordance with HFEA guidelines, so sex selection that relies on PGD is ruled out. *Id.*

were willing to defy the HFEA policy.[150] The HFEA renewed its ban of sex selection for nonmedical reasons on November 12, 2003.

England also strictly regulates the use of PGD to create "saviour siblings." The HFEA first announced in December 2001 that couples could use IVF and PGD to select an embryo that is a matched donor for an existing sick sibling.[151] The chair of the HFEA stated that such use could be justified, but that this was likely to happen "in very rare circumstances and under strict controls."[152] The HFEA outlined several conditions that must be met before the procedure could be used:

[1] All other possibilities of treatment and sources of tissue for the affected child should have been explored.

[2] The condition of the child should be severe or life-threatening.

[3] The technique should not be available where the intended tissue recipient is a parent.

[4] Couples undergoing this treatment should receive counseling.

[5] Embryos should not be genetically modified to provide a tissue match.[153]

The HFEA's announcement sparked immediate controversy, raising many concerns similar to those discussed in Part II.[154] The Comment on Reproductive Ethics ("CORE") immediately challenged whether the HFEA had the authority to grant IVF clinics licenses to carry out the procedure;[155]

150. Buxton, *supra* note 148; *Disappointment for Embryo Sex Selection Couple*, *at* http://www.bionews.org.uk/ new.lasso?storyid=823 (last updated Mar. 12, 2001). The HFEA is reviewing one loophole in its guidelines. McMillan, *supra* note 144, at 29. Under the Code of Practice, it is possible that a clinic that is not licensed could offer preconception gender selection techniques like sperm sorting. *Id.* The HFEA will likely move to make nonmedical sex selection illegal. *Id*.

151. *HFEA Allows PGD and Tissue Typing*, *at* http://www.bionews.org.uk/update.lasso? storyid =1114 (last updated Dec. 17, 2001).

152. *Id*.

153. Roger Highfield, *Fertility Authority Gives Go-Ahead for 'Designer Babies'*, THE DAILY TELEGRAPH (London), Dec. 13, 2001, at 9.

154. *Id*. Lord Winston, a fertility expert who helped develop PGD, stated that he feared that this use of PGD treated the new offspring as a "commodity." *Id*. He also questioned how parents would regard the child if the technique failed and whether it was fair to potentially subject the donor child to a lifetime of donating cells to a sibling. *Id*.

155. *See* The Queen v. Human Fertilisation Auth., 2003 P. 878, 883 (Eng. C.A.), *available at* 2003 WL 21047341. Josephine Quintavalle acted on behalf of CORE, a group whose purpose is "to focus and facilitate debate on ethical issues arising from human reproduction and, in particular, assisted reproduction." *Id*. A principal tenet of CORE is absolute respect for the human embryo. *Id*.

CORE was adamant that Parliament did not give this power to the HFEA.[156] A high court judge ruled that the HFEA did not have this legal power; but the HFEA appealed the ruling, and the ban was overturned by the Court of Appeal in April 2003.[157] Opponents of PGD are mounting a challenge in the House of Lords.[158]

Due to the global attention surrounding the Nash story, the HFEA had received an application for a similar use even before the 2001 announcement was made.[159] The Hashmi family sought to use PGD to conceive a donor child to help their young son, who is affected by the rare blood disorder thalassaemia.[160] Permission was granted by the HFEA in 2001.[161] The Hashmis resumed PGD after the Court of Appeals decision in April 2003, but stopped treatment in July 2004 after six unsuccessful attempts.[162] The couple's doctors were reluctant to continue because Mrs. Hashmi is forty years old, so the couple is now considering using two frozen embryos from previous treatments or trying gene therapy for their son.[163] The recent decision by the House of Lords means that the Hashmis could continue to try to create a "saviour sibling" to help their son.

156. *See* Josephine Quintavalle, *Creating Embryos for the Benefit of Sick Siblings: Whose Decision?*, *at* http://www.bionews.org.uk/commentary.lasso?storyid=1645 (last updated Apr. 22, 2003).

157. Buxton, *supra* note 148. For the entire opinion of the Court of Appeal, see *Human Fertilisation Auth.*, 2003 P. at 914–15 (holding that PGD, including "tissue typing," was governed by the Human Fertilisation and Embryology Act because the testing of an embryonic cell fell under the "concept of treatment services" within the meaning of the Act). The HFEA could therefore "allow tissue typing to test an embryo for tissue compatibility with an affected sibling." *Id*. at 915. Tissue typing, in brief, is a PGD technique that determines if an embryo has cells suitable to save the ill child. *See 'Saviour Sibling' Ruling to be Challenged*, *at* http://www.bionews.org.uk/new.lasso?storyid=1963 (last updated Jan. 28, 2004) [hereinafter *'Saviour Sibling'*].

158. The highest court ruled that the HFEA's decision to allow a family to create a "saviour sibling" was lawful. As a result, the HFEA can continue to issue licenses for families who want to create an IVF baby that could provide tissue-matched cord blood to treat a sick sibling. Josephine Quintavalle and CORE were "devastated" by the result. *Law Lords Back "Saviour" Siblings*, at http://www.bionews.org.uk/new.lasso?storyid=2542 (Apr. 28, 2005).

159. Highfield, *supra* note 153, at 9.

160. *Hashmis Fail in 'Saviour Sibling' Attempt*, *at* http://www.bionews.org.uk/new.lasso?storyid=2180 (July 9, 2004); Beezy Marsh, *The Sick Little Boy Science Won't Save*, DAILY MAIL (England), Aug. 2, 2002, at 1, *available at* 2002 WL 23510298; *see also* MOSBY'S, *supra* note 4, at 1604 (defining thalassemia as "a hemolytic hemoglobinopathy anemia characterized by microcytic, hypochromic, and short-lived red blood cells caused by deficient hemoglobin synthesis").

161. *Hashmis Fail in 'Saviour Sibling' Attempt*, *supra* note 160.

162. *Id.* (noting that the couple suffered one miscarriage and had three embryos in the last attempt that were perfect matches for their son, but they failed to develop in the womb).

163. *Id*.

The HFEA was heavily criticized when it refused another family's request to use PGD in the same way. The Whitaker family wanted to screen embryos to create a sibling to save their three-year-old son Charlie, who suffered from a rare form of anemia.[164] The HFEA denied the plan, however, and distinguished this from the Hashmis' situation because there is no apparent threat that Charlie's disorder has a genetic cause and therefore the PGD would be used solely to ensure a tissue match for him.[165] This would violate the HFEA rule that embryos can be screened only if it is to prevent a genetic disorder from being passed on.[166]

The plight of the Whitaker family prompted an outpouring of debate and support in the press, as well as questions whether the HFEA position should be changed.[167] The Whitakers received support from some doctors, including the

164. Marsh, *supra* note 160, at 5 (stating that Charlie suffers from Diamond-Blackfan anemia, meaning that his body does not produce a sufficient number of red blood cells and that he needs blood transfusions every three weeks and has a twelve-hour infusion into his stomach five nights per week); *see also* MILLER-KEANE ENCYCLOPEDIA & DICTIONARY OF MEDICINE, NURSING, & ALLIED HEALTH 96 (7th ed. 2003) (defining Diamond-Blackfan anemia as "idiopathic progressive anemia occurring in the first year of life, without leukopenia and thrombocytopenia; it is due to an isolated defect in erythropoiesis and is unresponsive to hematinics, requiring multiple blood transfusions to sustain life. For those responding to steroid therapy, the prognosis is good.").

165. Marsh, *supra* note 160, at 5; *see also* Sarah Boseley, *As Age of the Saviour Sibling Dawns, Pressure Mounts Inexorably to Change Embryo Rules*, THE GUARDIAN (London), June 20, 2003, at 3, *available at* 2003 WLNR 4550837 (explaining that there are only 600 to 700 children and adults with Charlie's condition in the world and therefore there is no high risk that a newborn sibling would also inherit the disease).

166. Marsh, *supra* note 160, at 5.

167. Juliet Tizzard, *Should PGD be Considered Case by Case?*, *at* http://www.bionews.org.uk/commentary.lasso?storyid=1344 (Aug. 12, 2002) (suggesting that the HFEA should reconsider PGD by not restricting access to it and by approving cases where the intention is to save or improve lives); *see also* George Wright, *Call for Debate over 'Designer Baby' Laws*, GUARDIAN UNLIMITED (United Kingdom), June 19, 2003, *at* http://www.guardian.co.uk/uk_news/story/0,3604,980740,00.html (quoting Liberal Democrat Member of Parliament, Evan Harris, who stated:

> It is high time that the government allowed proper public and parliamentary debate and amendment to the Human Fertility and Embryology Act to permit this sort of treatment. The Act is [thirteen] years old and is no longer up to date with clinical developments. The so-called positive selection of embryos with life-saving characteristics for siblings should be allowed since the exclusion, or so-called negative selection, of embryos with serious but non-fatal diseases is permitted.

Id. In response to the calls for a change in the law, the chair of the HFEA stated, "As the gap widens between the technology that was available when the act was passed in 1990, and the new technology available today, we may need to look at the act again." *Id.*; *see also* Martin Hutchinson, *Scientists Back 'Donor Babies'*, *at* http://news.bbc.co.uk/1/hi/health/3031830.stm (last updated June 30, 2003) (quoting Hans Evers, the chair of the European Society for Human Reproduction and Embryology, who stated, "The solution is morally acceptable if the use as a

British Medical Association.[168] After they were denied, the Whitakers traveled to the Reproductive Genetics Institute in Chicago, Illinois, to receive the treatment, and James Harry Whitaker was born in June 2003.[169] The couple later learned that the baby was a tissue match, and stem cells from James's umbilical cord were transferred to Charlie in July 2004.[170] Although there are early indications that Charlie is beating his illness, he will not be declared cured until one year after the transplant.[171]

In the aftermath of the Hashmi and Whitaker stories, and the statements of the chair of the HFEA, the Science and Technology Committee of the United Kingdom House of Commons announced in October 2003 that it would examine whether the Human Fertilisation and Embryology Act was still working effectively.[172] The Committee had previously called for the Act to be updated in 2002, but the government failed to take action.[173] In late July 2004, the HFEA announced that no distinction should be made between the cases of the Hashmi family and the Whitaker family—PGD would be allowed for the sole purpose of tissue typing.[174] The HFEA emphasized that an application to perform the procedure must be accompanied by evidence from the clinical team treating the sick child and that all other alternatives must first be exhausted.[175]

B. Germany

In sharp contrast to England and the United States, Germany has traditionally outlawed PGD.[176] No German law outright forbids PGD, nor is

donor is not the only motive for the parents to have the child—they intend to love and care for this child to the same extent as they love and care for the affected child.").

168. Boseley, *supra* note 165, at 3.

169. *Id*.

170. *Charlie Whitaker Has Stem Cell Transplant*, *at* http://www.bionews.org.uk/new.lasso?storyid=2210 (July 28, 2004).

171. *Id*.

172. *Human Fertilisation Act Under Scrutiny*, *at* http://www.bionews.org.uk/new.lasso?storyid=1868 (Oct. 27, 2003).

173. *Id*.

174. *HFEA Allow PGD for HLA Tissue Typing*, *at* http://www.bionews.org.uk/new.lasso?storyid=2200 (July 22, 2004) (noting that the chair of the HFEA stated, "Our review of available evidence does not indicate that the embryo biopsy procedure disadvantages resulting babies . . . risks associated with sibling to sibling stem cell donation are low"); *see also Fletchers Given 'Saviour Sibling' Go-Ahead*, *at* http://www.bionews.org.uk/new.lasso?storyid=2259 (Sept. 6, 2004) (describing how the HFEA granted permission for a couple to use PGD to conceive a baby who could provide umbilical cord blood cells to their son, who suffers from the rare blood condition Diamond-Blackfan anemia).

175. *HFEA Allow PGD for HLA Tissue Typing*, *supra* note 174.

176. German National Ethics Council, *Genetic Diagnosis Before and During Pregnancy* (stating that it is controversial whether PGD is within the Embryo Protection Law), *at* http://www.ethikrat.org/_english/main_topics/pndpgd.html (last visited Nov. 2, 2004); *see also*

the term mentioned in any federal law.[177] The government, however, did enact the Embryo Protection Law, which was intended to protect embryos from "improper use" and to prevent modern reproductive technologies from being abused.[178] PGD has been uniformly opposed by all German political parties.[179] Performing any embryological research was viewed as entering the slippery slope that might lead to a population policy similar to that implemented by Nazi Germany.[180]

German law appears somewhat inconsistent, as the selection of healthy embryos before pregnancy is prohibited, but an abortion several weeks later with the same medical indications is allowed.[181] The focus of the German decision-making process is the woman and not the fetus.[182] Additionally, Germany has enacted guidelines for the use of IVF, which is only permitted for treatment of an infertile couple, and has established regulations for the Federal Physicians Chamber, which also forbids the use of PGD.[183]

The German Medical Association has concluded that if PGD was allowed, its potential misuse could be prevented by excluding sex selection for social

Harris, *supra* note 141, at 359 (discussing Germany's approach to stem cell and embryo research). The author notes that abortion is permissible for a variety of reasons, that the abortion pill RU-486 is available, but that research on embryos is prohibited. *Id.*; *see also* Nicole Richardt, *A Comparative Analysis of the Embryological Research Debate in Great Britain and Germany*, 10 SOC. POL. 86, 89 (2003) (noting that, unlike England, the German law does not separate the early states of life from the later ones and thus the embryo is granted in vitro personhood status). Therefore, all kinds of embryological research are prohibited, PGD is not available, and embryo selection during infertility treatment is avoided by limiting the number of fertilized eggs that can be implanted into the womb. *Id.*

177. M. Ludwig et al., *The Situation of Preimplantation Genetic Diagnosis in Germany: Legal and Ethical Problems*, 20 PRENATAL DIAGNOSIS 567, 567 (2000), *available at* http://www3.interscience.wiley.com/cgi-bin/fulltext/72512975/PDFSTART (published online July 21, 2000). *But see* FUKUYAMA, *supra* note 18, at 205 (noting that since passing the embryo law in 1990, Germany has regulated areas such as abuse of human embryos, sex selection, and cloning, among others).

178. Stefan Mueller, *Ethics and the Regulation of Preimplantation Diagnosis in Germany*, 7 EUBIOS J. ASIAN & INT'L BIOETHICS 5, 5–6 (1997), *available at* http://www.biol.tsukuba.ac.jp/~macer/EJ71/EJ71D.html.

179. Richardt, *supra* note 176, at 110.

180. *Id.* The common good and the interests of society as a whole were the basis for the rejection of embryological research in Germany. *Id.* In England, however, the effects of such legislation were judged on the basis of the effects on an individual. *Id.*

181. Mueller, *supra* note 178, at 5–6. "Termination is permitted when a prospective mother believes that she cannot manage her future life if her child is affected with a genetic condition or when the woman has a life-threatening medical or psychiatric condition that would be adversely affected by the birth of a child." Ludwig et al., *supra* note 177, at 567.

182. Ludwig et al., *supra* note 177, at 569.

183. Mueller, *supra* note 178, at 5–6; *see also* Richardt, *supra* note 176, at 90 (noting that although embryological research is prohibited, Germany does permit ARTs, which the medical profession regulates through internal codes and guidelines).

reasons as well as genetic conditions having little or no impact on children's health.[184] A main argument in support of legalization is that termination of a pregnancy after more traditional prenatal diagnosis could be avoided.[185] But the debate continues—although a couple's desire to have children should be taken seriously, some feel that does not imply an inalienable right to PGD.[186]

There is some indication that the German government might begin to revise its opinion. In early 2003, the National Ethics Council issued a press release in which the Council "unanimously recommends regulating the use of . . . [PGD] in a special comprehensive reproductive medicine law."[187] The statement elaborated:

> [T]he National Ethics Council consequently does not consider it to be its task to embrace a particular regulatory arrangement or indeed to recommend that arrangement to lawmakers as ultimately the only possible option.
>
> The Council's job is, rather, to develop arguments and point out possible solutions connected with these arguments. It must be left to parliament to choose the legislative path that, in its view and in cognizance of these arguments, is appropriate.[188]

While all Council members agreed that some sort of comprehensive law should be adopted, they differ in whether the use of PGD in Germany should be allowed. Nine out of twenty-five members still favor no use of PGD in Germany at all.[189] A majority of Council members (fifteen of twenty-five) favor introducing legislation to allow PGD to be used to screen for "serious genetic disorders which cause conditions that can not [sic] be treated, serious chromosome disorders, and for the treatment of infertile couples if the use of

184. Ludwig et al., *supra* note 177, at 569 (recommending that couples at risk for having children with a severe genetic disease be permitted to use PGD).

185. Briefing of the Institut Mensch, Ethik, and Wissenschaft, *Preimplantation Genetic Diagnosis—A Questionable Procedure*, *at* http://www.imew.de/index_en.php/action/article/aid/83 (Jan. 2003).

186. *See generally id.* (identifying similar concerns as those raised in the United States and stating that restricting PGD to serious disorders is not possible, nor is review of each individual case by a central ethics committee, which would be a "scarcely justifiable invasion of the autonomy of the couples concerned").

187. Press Release, National Ethics Council, National Ethics Council Presents its Opinion on Preimplantation Genetic Diagnosis, *at* http://www.ethikrat.org/_english/press/Ethics_Council_PR_2003_01.pdf (Jan. 23, 2003) [hereinafter Press Release]. *But see* Richardt, *supra* note 176, at 116 (noting that a significant resistance toward PGD and embryological research remains).

188. Press Release, *supra* note 187; *see also* Richardt, *supra* note 176, at 117 (noting that "[t]he council also recommended to regulate all questions concerning reproductive medicine in a Reproductive Medicine Act and, thus to revise the Embryo Protection Act") (citation omitted).

189. Ursula Roos, *German Ethics Council Publishes Report on Preimplantation Genetic Diagnosis*, *at* http://www.britischebotschaft.de/en/embassy/r&t/notes/rt-note03.2010_german_ethic_council.html (Feb. 4, 2003).

PGD would increase the chances of successful infertility treatment."[190] These members, however, would also establish several limitations on use before the ban is removed.[191] For example, couples should receive adequate counseling on ethical, medical, psychological, and social aspects of the procedure; licenses should be given to a limited number of centers; and regulations should be devised to ensure that PGD is used for only specific indications.[192]

The sentiment of the German public is similar to that of the National Ethics Council. A study by German researchers of both infertile couples and the general population revealed that current legislation is "out of step" with public attitudes towards the use of PGD, egg donation, and surrogacy.[193] Although the results showed that Germans were not well-informed about PGD or assisted reproductive procedures, the majority thought that PGD should be allowed for the detection of genetic diseases in embryos.[194] High percentages of both groups were against the use of PGD for sex selection or non-disease related reasons.[195] Perhaps the feelings of the general public and the National Ethics Council will prompt the German government to reconsider its current position.

C. Australia

IVF has a long history in Australia. Approximately two percent of all babies born there are conceived as a result of IVF, and after the world's first IVF baby was born in England, twelve of the next fourteen IVF babies were born in Australia.[196] In Australia, PGD is offered by IVF clinics.[197] ARTs are being used almost entirely to treat infertility and prevent genetic disease.[198]

PGD is as controversial a topic in the Australian media as it is elsewhere in the world. Though the Sydney IVF clinic is where couples first sought treatment, more clinics are being granted conditional approval for the process by the Infertility Treatment Authority ("ITA").[199] In 2002, the ITA in the state

190. *Id*.

191. *Id*.

192. *Id*.

193. *German Study Shows Support for Assisted Reproduction*, *at* http://www.bionews.org.uk/new.lasso?storyid=2162 (June 28, 2004).

194. *Id.*

195. *Id*.

196. Mandi Zonneveldt, *Doing God's Work*, SUNDAY TELEGRAPH (New South Wales, Australia), June 29, 2003, at 92, *available at* 2003 WL 64848534 (also noting that "IVF is now considered a norm, rather than a heinous idea from the realms of science-fiction," but that it still has its detractors in the Catholic Church and right-to-life activists).

197. Julian Savulescu, *Sex Selection: The Case For*, 171 MED. J. AUSTL. 373, 373 (1999), *available at* http://www.mja.com.au/public/issues/171_7_041099/savulescu/savulescu.html.

198. *Id*.

199. Judy Skatssoon, *The Age of the Designer Baby Dawns*, AUSTRL. ASSOCIATED PRESS GENERAL NEWS, Apr. 17, 2002, *available at* 2002 WL 18029234 (noting that the Sydney IVF

of Victoria gave permission to Roman Curkowskyj and Tania Kutny, the parents of a toddler suffering from Fanconi's anemia, to use PGD to conceive a sibling in an attempt to save her life.[200] Until then, Australia had outlawed such tissue typing and the notion of saviour siblings.[201] The ITA now considers applications for HLA tissue matching and PGD on a case-by-case basis.[202]

The different states within Australia decide how to regulate PGD and IVF. The ITA has stated that its understanding of the Infertility Treatment Act 1995 is that PGD should be used "only for those conditions or abnormalities which will significantly adversely affect the health of a person[] who may be born."[203] The ITA is a statutory authority with responsibility for administering provisions of the Act.[204]

Sex selection for nonmedical reasons receives great debate in Australia and is becoming more common. The Sydney IVF clinic allowed 120 couples to use PGD to select the sex of their child for purely social reasons in 2002 alone.[205] Somewhat surprisingly, sixty-four percent of parents wanted a girl, and the most common reason for undergoing the procedure was family

clinic "prides itself" in its expertise in this field and that at the Melbourne IVF clinic one couple was granted conditional approval); *see also Clinic Testing for Genetic Disorders*, CANBERRA TIMES (Australia), Dec. 20, 2003, at 6, *available at* 2003 WL 70551583 (reporting that a clinic in Canberra has begun to offer PGD testing).

200. Vikki Leone, *Babies by Design*, THE AGE (Australia), Apr. 24, 2002, at 11, *available at* 2002 WL 19619029. For a definition of Fanconi's anemia, see *supra* note 4.

201. Leone, *supra* note 200 (noting that the procedure could only be used for a sibling and that individual cases had to be approved by an ethics committee).

202. Infertility Treatment Authority, *Tissue Typing in Conjunction with Preimplantation Genetic Diagnosis* § 2.2, *at* http://www.ita.org.au/_documents/policies/policy_PGD_HLA_matching.pdf (reviewed Jan. 2003). These guidelines also state that the donor child can only provide cord blood or bone marrow. *Id.* "The harvesting of 'hard' or non-regenerative organs is not acceptable." *Id.*; *see also Australian Couples to Have 'Saviour Siblings'*, *at* http://www.bionews.org.uk/new.lasso?storyid=2017 (Mar. 15, 2004) (noting that the president of the Australian Medical Association said, "The AMA would not sanction the selection of an embryo simply to produce a child exclusively to help treat an existing sibling," but if the parents' intent was to create a child that is disease free and could help a sick sibling, "then it could be argued that is ethically correct.").

203. Infertility Treatment Authority, *Genetic Testing and the Requirements of the Infertility Treatment Act 1995* § 1, *at* http://www.ita.org.au/_documents/licencing/PGD_Policy_January_04.pdf (updated Jan. 2004). This site also summarizes legal requirements, ethical considerations, when notification of using PGD is required, criteria for assessment of applications, and the mechanism for appeal in case the application is denied. *Id.* at §§ 2–6.

204. *Id.* at § 2.

205. Zoe Taylor, *Designer Babies a Growing Trend*, COURIER MAIL (Queensland, Australia), Nov. 10, 2003, at 3 (noting that more than 250 couples have used PGD for sex selection since 1995).

balancing.[206] A well-known advocate for sex selection, Julian Savulescu, argues that "[i]t is totalitarian for the State to dictate which children parents should have and rear."[207] In Victoria, § 50(2) of the Infertility Treatment Act 1995[208] explicitly bans sex selection employing artificial insemination or IVF for non-medical reasons.[209] In South Australia, artificial fertilization can only be used for the treatment of infertility under § 13 of the Reproductive Technology Act 1988.[210] Each of these Acts provides exceptions to avoid the risk of transmitting a genetic defect.[211] New South Wales is considered to have some of the most liberal guidelines in Australia, as the hard decisions are made by ethics committees at the IVF clinics—not a state regulatory body.[212]

IV. ANALYSIS: IS IT POSSIBLE TO REGULATE PGD BASED ON THE PARENTS' INTENT?

As seen in the preceding section, some nations regulate and restrict the use of PGD much more than the United States. But the use of PGD for sex selection that has already occurred in Australia and the United States demonstrates that this practice—and using PGD to select solely for non-therapeutic traits—could become increasingly common.[213] The federal government needs to regulate this technology by enacting legislation to ensure that it is not used in non-therapeutic ways. The primary argument against regulating PGD or any ART is that regulation would violate procreative liberty, but there is also strong support that procreative liberty is not a limitless right.[214] This Section argues that legislation could be drafted in such a way that would limit the uses of PGD based on the parents' motivation for

206. *Id.* (also noting that other reasons were a desire for a particular parent–child relationship and a desire to replace a child who had died or been lost in pregnancy).

207. Savulescu, *supra* note 197, at 374–75 (also noting that "'[p]rocreative autonomy' is the liberty to decide when and how to have children according to what parents judge is best. Parents know best their own circumstances, and ultimately it is parents who must live with and make sacrifices for their children.").

208. Infertility Treatment Act, 1995, § 50 (Vic.).

209. Savulescu, *supra* note 197, at 373–74.

210. *Id.*

211. *Id.*

212. *See, e.g.*, Zonneveldt, *supra* note 196.

213. *See* Malinowski, *supra* note 61, at 223–24 (suggesting that the motion picture *Gattaca* "depicts a United States society in the not-too-distant future obsessed with genetic perfection in which ART and PGD are the standard of care for conceiving a child." The author notes that when the movie was released in 1997, the biotechnology industry characterized the film as science fiction. Now, however, "[r]enowned bioethicists . . . respected broadcast journalists, and others are referring to *Gattaca* as a prophetic depiction of the society we could become.") (footnote omitted).

214. *See infra* Parts IV.A.1–2, IV.B.2.

undergoing the procedure and also demonstrates why it should be regulated from a public policy perspective.

A. Argument that PGD Should Be Used for Any Purpose

1. Explanation of Procreative Liberty

In the United States, proposals for greater social oversight of any ART, including PGD, prompt us to question "the allocation of authority between individuals and society in the area of reproductive decision-making."[215] If one views the decision as a private matter, then it would be protected from society's control, and the role of public policy would be quite limited.[216] If one views this decision as a species-level issue, then individual preferences should give way to a collective determination of the overall social good.[217] This view supports restricting or prohibiting practices that are considered to be "inconsistent with overall social welfare."[218]

Resolving these views largely depends on the way in which the United States Supreme Court interprets procreative liberty.[219] A finding that ARTs

215. Carl H. Coleman, *Assisted Reproductive Technologies and the Constitution*, 30 FORDHAM URB. L.J. 57, 59 (2002); *see Attitudes About Reproductive Genetics*, *supra* note 84 (noting that "[m]ost respondents think the government should regulate the quality and safety of reproductive genetic technologies and limit human cloning." The fears about ARTs are that they are too much like "playing God" (thirty-four percent) or that "they can be easily used for the wrong purposes" (thirty-five percent).).

216. Coleman, *supra* note 215, at 59–60 (suggesting public policy would be "limited to purposes such as facilitating informed decisions by individuals, enhancing the quality of services by ART practitioners, and clarifying the parental rights and responsibilities of persons involved in the process") (footnotes omitted); *see also* John A. Robertson, *Genetic Selection of Offspring Characteristics*, 76 B.U. L. REV. 421, 422–23 (1996) (stating that "[i]f people are generally free to choose whether or not to reproduce, and if the genetic characteristics of expected offspring will affect that decision, it would appear that prospective parents should be free to use genetic information in making those decisions"). Yet Robertson also recognizes that shaping offspring traits seems to be "an unprecedented exercise of control over the lives" that "could lead to viewing children as commodities[] and undermine their inherent worth and dignity." *Id.*

217. Coleman, *supra* note 215, at 59–60.

218. *Id.*

219. *Id.* at 60; *see also* RONALD DWORKIN, LIFE'S DOMINION 148 (1993) (defining procreative autonomy as the right of individuals "to control their own role in procreation unless the state has a compelling reason for denying them that control"); JOHN A. ROBERTSON, CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES 16, 22–23 (1994) [hereinafter ROBERTSON: CHILDREN OF CHOICE). Robertson describes the principle of procreative liberty as protecting "the freedom to decide whether or not to have offspring and to control the use of one's reproductive capacity." *Id.* at 16. He defines procreative liberty as "the freedom to reproduce or not reproduce in the genetic sense." *Id.* at 22–23. Procreative liberty is so important because "control over whether one reproduces or not is central to personal identity, to dignity, and to the meaning of one's life." *Id.* at 24. Robertson also notes that the "liberty" in procreative liberty is a negative right, meaning that "a person violates no moral duty in making a

are a constitutionally protected interest might preclude outright prohibitions on their use, but if these decisions do not warrant special constitutional protection, then the government could regulate in virtually any manner it chooses.[220] Opponents of regulation fear that if the government implemented some sort of regulation, it would be incapable of limiting the scope of regulations.[221]

Constitutional analysis of ART relies on a great deal of speculation, as the Supreme Court has never recognized outright a constitutional right to procreate,[222] but John Robertson, a leading authority on procreative liberty, believes that it exists.[223] Because of his prominence within the field, the views presented in this Section will primarily be based on his writings and theories. Robertson notes two types of procreative liberty: the freedom to avoid reproduction and the freedom to reproduce (procreate).[224] The freedom to avoid reproduction is thought to be implied in the Court's cases dealing with contraception and abortion.[225] The freedom to procreate causes considerably more debate.

procreative choice, and that other persons have a duty not to interfere with that choice." *Id.* at 23 (footnote omitted). Similarly, procreative liberty is a "negative right against state interference with choices to procreate or to avoid procreation." *Id.*

220. Coleman, *supra* note 215, at 60.

221. Alexander N. Hecht, Comment, *The Wild Wild West: Inadequate Regulation of Assisted Reproductive Technology*, 1 HOUS. J. HEALTH L. & POL'Y 227, 235 (2001).

222. Coleman, *supra* note 215, at 61.

223. *See generally* ROBERTSON: CHILDREN OF CHOICE, *supra* note 219.

224. *Id.* at 25.

225. *See* Griswold v. Connecticut, 381 U.S. 479, 485 (1965) (protecting the right of married couples to use contraceptives); Eisenstadt v. Baird, 405 U.S. 438, 453–55 (1972) (extending the right to use contraceptives to unmarried people); Roe v. Wade, 410 U.S. 113, 164–66 (1973) (establishing a woman's constitutional right to a previability abortion and holding that states only have a compelling interest in potential human life, thus allowing them to restrict or prohibit abortion only after viability); Planned Parenthood v. Casey, 503 U.S. 833, 846 (1992) ("retaining and once again reaffirm[ing]" the "essential holding of *Roe v. Wade*"). The Court also noted that "it is clear that among the decisions that an individual may make without unjustified government interference are personal decisions 'relating to marriage, procreation, contraception, family relationships, and child rearing and education.'" *Id.* at 2811 (quoting Carey v. Population Servs. Int'l, 431 U.S. 678, 684–85 (1977)); *see also* Lifchez v. Hartigan, 914 F.2d 260 (7th Cir. 1990), *aff'g* 735 F. Supp. 1361, 1377 (N.D. Ill. 1990) (noting that if the right to privacy includes the right to avoid reproduction, it should also include "the right to submit to a medical procedure that may bring about, rather than prevent, pregnancy"); Jean E. Chambers, *Women's Right to Choose Rationally: Genetic Information, Embryo Selection, and Genetic Manipulation*, 12 CAMBRIDGE Q. OF HEALTHCARE ETHICS 418, 419–20 (2003) (assuming that if a woman has the right to abort a pregnancy for any reason, then she trivially has "a derivative right to abort any specific pregnancy for any specific reason"). Chambers states:

> This right suggests a corally de facto right to refuse to implant any particular candidate embryo, given that it would be futile and unnecessary costly to implant an embryo that would be aborted later. Implantation of some embryo or other is not mandatory, because reproduction is not mandatory . . . [t]hus the candidate embryos are effectively at the

Robertson suggests that the freedom to procreate involves the freedom to engage in actions that result in reproduction and usually in child rearing.[226] The primacy of procreation is not limitless, but the standard for limiting the right is presumed to be high.[227]

If a right to procreate exists, it has been suggested to be grounded in the right to privacy.[228] Yet, the Court has never defined precisely what privacy protects.[229] Robertson acknowledges that explicit law concerning the right to procreate is lacking, but references dicta in Supreme Court decisions to suggest that the right does, in fact, exist.[230] Robertson also believes that if the moral right to reproduce presumptively protects coital reproduction, then it should also protect noncoital reproduction.[231] He states that, "if bearing, begetting, or parenting children is protected as part of personal privacy or liberty, those experiences should be protected whether they are achieved coitally or

> women's disposal. It would be morally permissible for her to refuse to implant any of them.

Id.; *see also* June Coleman, Comment, *Playing God or Playing Scientist: A Constitutional Analysis of State Laws Banning Embryological Procedures*, 27 PAC. L.J. 1331, 1365 (1996) (stating that "[t]he right to procreative freedom also justifies preimplantation diagnostic testing, fitting squarely within the fundamental rights outlined in the abortion cases because of this procedure's connection to reproduction through in vitro fertilization").

226. ROBERTSON: CHILDREN OF CHOICE, *supra* note 219, at 30.

227. *Id.* at 30 (stating that the two-step analysis is "whether a distinctively procreative interest is involved" and if so, "whether the harm threatened by reproduction satisfies the strict standard for overriding this liberty interest").

228. Radhika Rao, *Reconceiving Privacy: Relationships and Reproductive Technology*, 45 UCLA L. REV. 1077, 1093 (1998) (noting that "[i]f the Constitution guarantees a right of procreation, such a guarantee must fall within the ambit of the amorphous right to privacy"); *see Eisenstadt*, 405 U.S. at 453 (stating that "[i]f the right of privacy means anything, it is the right of the *individual*, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child"); Paris Adult Theatre I v. Slaton, 413 U.S. 49, 66 n.13 (1973) ("[T]he constitutionally protected privacy of family, marriage, motherhood, procreation, and child rearing is not just concerned with a particular place, but with a protected intimate relationship.").

229. *See* Rao, *supra* note 228, at 1102–03. Privacy protects only those personal rights that are deemed fundamental in the concept of ordered liberty. *See Paris Adult Theatre I*, 413 U.S. at 65. Conduct between two "consenting adults" does not automatically give rise to constitutional protection. *See id*. at 68.

230. *See generally* ROBERTSON: CHILDREN OF CHOICE, *supra* note 219, at 35–38 (identifying the strongest precedent to be dicta in *Skinner v. Oklahoma*). In *Skinner*, the Court stated that marriage and procreation were among "the basic civil rights of man" and "are fundamental to the very existence and survival of the race." 316 U.S. 535, 541 (1942).

231. ROBERTSON: CHILDREN OF CHOICE, *supra* note 219, at 32 (noting that "[t]he moral right of the coitally infertile to reproduce is based on the same desire for offspring that the coitally fertile have"). Robertson also notes, however, that the major question is whether the technology used truly implicates reproductive interests, making this a common problem arising with technologies that select offspring characteristics. *See id*. at 32–33.

noncoitally . . . with the state having the burden of showing severe harm if the practice is unrestricted."[232]

2. Does Procreative Liberty Protect All Uses of PGD?

Robertson imposes relatively few limits on procreative liberty. He goes so far as to argue that quality control devices, such as genetic screening or selective abortion, become part of the liberty interest in procreating or avoiding procreation and thus should receive the same degree of protection.[233] However, Robertson does realize that practices such as non-therapeutic enhancement "may so deviate from the core interests that make reproduction meaningful as to fall outside the protective canopy of procreative liberty."[234]

Although Robertson's *Children of Choice* was published six years before the Nash family ever used PGD to conceive baby Adam to serve as a tissue match, Robertson discussed whether having a child to serve as a tissue donor for an existing child was within the protective realm of procreative liberty. He concluded that conceiving a child to be a marrow donor is not any worse than the myriad other reasons for which children are sought.[235] Even if an actual bone marrow transplant is required instead of merely cord blood, the risks and burdens to the donor child fit within the range of parental discretion over a

232. *Id*. at 39; *see also* John A. Robertson, *Assisted Reproduction and the Family*, 47 HASTINGS L.J. 911, 914 (1996) (stating that "laws that restrict or prohibit access to ARTs should be judged under the same exacting standard that would apply to direct restrictions on coital reproduction—the need to show a compelling state interest not achievable by less restrictive means") (citing Griswold v. Connecticut, 381 U.S. 479, 503–04 (1965) (White, J., concurring)). A state's power to ban ARTs is greatly limited, but it can implement "regulatory measures that guide and discourage, rather than coerce and prohibit. There is . . . room for regulatory efforts that aim to enhance and protect autonomy, rather than to restrict it totally." *Id.* at 915.

233. ROBERTSON: CHILDREN OF CHOICE, *supra* note 219, at 33 (noting that often a couple's decision to reproduce is dependent on the ability to have healthy children); *see also* Robertson, *Genetic Selection of Offspring Characteristics*, *supra* note 216, at 426–27 (stating that if the decision to reproduce is a fundamental right, then a large measure of prebirth control over offspring traits and characteristics should follow). Robertson reasoned:

> If a person would choose not to reproduce if she knew that the child would have a disability or some other undesired characteristic, then she should be entitled to have that information and act on it. Her right to avoid reproduction for any reason would entitle her to avoid reproduction for a particular reason. Similarly, her right to have offspring generally should entitle her to have offspring only if she thinks that offspring will have particular characteristics.

Id. at 427.

234. ROBERTSON: CHILDREN OF CHOICE, *supra* note 219, at 34. Robertson states that there may be disagreement as to where the deviation point is, but it will not easily exclude most reproductive technologies. *Id.* at 41.

235. *Id.* at 215.

child.[236] As long as the parents will act for the best interests of the donor child once it is born, their motives for having the child should not matter.[237]

When considering selection of offspring characteristics, Robertson believes that prenatal interventions to cure disease or defect at the fetal or embryo level should be permitted.[238] Seeking to have children is an important aspect of procreative liberty, and thus therapeutic actions designed to prevent serious disease or defect in expected offspring are part of that liberty.[239]

Robertson correctly notes that a more difficult question is embryo selection for less serious conditions, for susceptibility traits, and for gender.[240] Robertson seems inclined to allow such screening, as he notes that because the embryo is so rudimentary in development, selection of embryos for these reasons is less objectionable than screening fetuses for those reasons.[241]

3. Right of Parental Discretion When Caring for Children

Robertson also recognizes that parents have broad parental discretion in rearing offspring once they are born, which makes it difficult to argue that PGD should be excluded from parental choice.[242] The Court has long recognized that parents' interest in rearing their children according to their own preferences is constitutionally protected,[243] but has also realized that parental

236. *Id.* at 215–16 (recognizing that parents are ordinarily free to have minor children serve as donors to ill siblings).

237. *Id.* at 217.

238. *Id.* at 151 (noting that the perceived dangers of these types of quality control appear to be insufficient to justify removing these choices from the discretion of couples planning to reproduce).

239. ROBERTSON: CHILDREN OF CHOICE, *supra* note 219, at 161.

240. *Id.* at 156. At the time of his writing, 1994, it was not yet possible to screen embryos for most or all of those reasons, so Robertson was merely speculating on the possibility that this might eventually be possible. As stated in Part II, it is now possible to test for each of those reasons.

241. *Id.* It is again important to notice the timing of these comments. Robertson speculates that "[*e*]*ven* gender selection might be acceptable at this stage because the expense and burdens of the practice make it unlikely that this technique would ever be so widespread as to alter societal sex ratios—a main concern with gender selection." *Id.* (emphasis added). As mentioned above in Parts II and III, gender selection has become a reality. In his book, Robertson also discusses the concern of the "slippery slope," but feels that "the fear that something will occur in the future is rarely a sufficient reason to stop an otherwise acceptable action from occurring." *Id*. What Robertson alluded to as "fears" in 1994 have in fact become reality.

242. *Id.* at 164; *see also* Robertson, *Genetic Selection of Offspring Characteristics*, *supra* note 216, at 436–37 (stating that if states cannot show that enhancement activities harm the child, then prebirth enhancement may receive protection as part of the right to rear children, even if it were not independently protected by procreative liberty).

243. *See* Pierce v. Soc'y of Sisters, 268 U.S. 510, 534–35 (1925) (holding that a state law that required attendance at public schools violated parents' liberty interest in directing the upbringing of their children).

rights are not limitless.[244] Robertson does recognize that any type of genetic enhancement may likely have a far greater impact on offspring than any parental efforts made after the child was born, but feels that the potential "slippery slope" argument should not deny parents the right to alter embryos for therapeutic purposes.[245] As long as the intervention is safe and likely to benefit offspring, it is no more likely to objectify or commodify offspring than postnatal enhancement efforts already do.[246] The acceptability of prenatal enhancement may depend on the risks and benefits when compared to postnatal enhancement, and not on "procreative liberty per se."[247]

B. The "Rights" to Procreate and to Parental Discretion Are Not Broad Enough to Justify the Use of PGD for Non-Therapeutic Reasons

1. The Scope of the Right to Privacy Is Much Narrower

Commentators are willing to accept that a married couple's choice to reproduce by sexual intercourse warrants constitutional protection under current privacy doctrine.[248] Additionally, the Supreme Court's jurisprudence in privacy and abortion cases establishes the right not to procreate.[249] It is less clear, however, whether the right of privacy also extends to reproduction without sexual intercourse, and the courts have rarely addressed the constitutionality of restrictions on techniques of assisted reproduction.[250] The

244. *See* Prince v. Massachusetts, 321 U.S. 158, 168 (1944) (holding that the state can limit parental freedom if the child's welfare is affected, regardless of whether the parents' decisions are based on religious grounds).

245. *See* ROBERTSON: CHILDREN OF CHOICE, *supra* note 219, at 164.

246. *Id.*

247. *Id.* at 167.

248. *See* Rao, *supra* note 228, at 1096 (noting that the case of *Griswold v. Connecticut* suggests, but does not expressly affirm, that sexual reproduction falls within the scope of marital privacy). *See generally* Griswold v. Connecticut, 381 U.S. 479 (1965).

249. *See generally supra* note 225. *See also* Ann MacLean Massie, *Regulating Choice: A Constitutional Law Response to Professor John A. Robertson's Children of Choice*, 52 WASH. & LEE L. REV. 135, 148 (1995) (referencing, among other decisions, *Griswold*, *Eisenstadt*, and *Roe*). It should be noted that Robertson's book was the subject of a symposium at Washington & Lee University School of Law in 1995. For a wide range of critiques of his work, and for Robertson's response, see Lindsay King, *Introduction*, 52 WASH. & LEE L. REV. 133 (1995). *See also* Jeffrey R. Botkin, *Prenatal Diagnosis and the Selection of Children*, 30 FLA. ST. U. L. REV. 265, 285 (2003). "[W]omen have a right to decide whether they wish to remain pregnant at all; they might not have the right to decide whether they wish to remain pregnant with a specific fetus." *Id*. at 285. Similarly, women may not have a right to decide which specific embryo to implant for non-therapeutic reasons.

250. Rao, *supra* note 228, at 1081–82; *see also* Lori B. Andrews & Nanette Elster, *Regulating Reproductive Technologies*, 21 J. LEGAL MED. 35, 45 (2000) (noting that the right to make reproductive decisions "includes the right of an infertile couple to utilize medically assisted reproduction," but "[h]ow far this right extends or what limits can be imposed on this right are

Court has not had an opportunity to discuss whether parents have a fundamental right to choose the traits of their children.[251]

The social dimension of the right to privacy has not been recognized, but "[p]rivacy does not simply guarantee individuals the right to sexual, reproductive, and parental autonomy. It protects the relationships between people that develop in the course of these activities, rather than the individual's solo right to engage in such activities."[252] Within these close personal relationships, "privacy secures the freedom to conduct intimate and consensual associations, while the rights of bodily integrity and equal protection work together to afford constitutional protection to particular acts involved in procreation."[253]

Privacy cases in support of procreative liberty do not extend so far as to protect all possible behaviors relating to the choice of whether "to bear or beget a child."[254] Couples wishing to conceive using ART need access to the technology and thus have more specific interests than just the right to procreate. All methods of assisted reproduction may not be protected by procreative liberty because, unlike coital reproduction, they do not directly implicate the values that are pertinent to the privacy cases, such as "bodily integrity, marital intimacy, or integrity of the family unit."[255] Furthermore, Robertson's reliance on *Skinner v. Oklahoma*[256] as the sole precedent supporting the constitutional right to procreate has faced criticism and skepticism. The *Skinner* holding may rest "upon the constitutional right to privacy of a person, which prohibits state intrusions upon bodily integrity."[257]

continually being debated" and disputes exist about what activities constitute protected reproduction).

251. Skylar A. Sherwood, Note, *Don't Hate me Because I'm Beautiful . . . and Intelligent . . . and Athletic: Constitutional Issues in Genetic Enhancement and the Appropriate Legal Analysis*, 11 HEALTH MATRIX: J. OF LAW-MEDICINE 633, 639–40 (2001) (stating that "[c]hoosing to genetically engineer one's child involves the question of whether there is a right to genetically enhance, not whether one will have a child").

252. Rao, *supra* note 228, at 1103. It is incorrect "to equate privacy with a general constitutional right to engage in any or all . . . important activities free from governmental interference." *Id*. at 1078.

253. *Id*. at 1113–14 (citation omitted). For Rao's complete discussion on this point, see *id*. at 1101–13. Relational privacy encompasses a couple's right to combine their own gametes with the assistance of reproductive technologies, including the use of IVF. *Id*. at 1116–17.

254. *See* Massie, *supra* note 249, at 159 (noting that cases defining constitutionally protected conduct implicate the values of bodily integrity and social concerns, such as the privacy of marital intimacy and the integrity of the family unit, in addition to the values of self-fulfillment and self-definition emphasized by Robertson); *see also* Botkin, *supra* note 249, at 285 (stating that privacy rights cannot be used to compel the provision of genetic information, even if the information will be used in a private matter).

255. Massie, *supra* note 249, at 162.

256. 316 U.S. 535 (1942).

257. Radhika Rao, *Constitutional Misconceptions*, 93 MICH. L. REV. 1473, 1484–85 (1995).

Under this rationale, *Skinner* would only protect the right to refuse abortion and carry a coital pregnancy to term and the right to resist compulsory contraception or sterilization.[258] Therefore, it is "not at all clear that *Skinner* extends constitutional protection to noncoital methods of reproduction, such as artificial insemination and in vitro fertilization."[259]

Finally, although the decision to procreate is a very important one, the Court has made it clear that not all deeply personal choices receive constitutional protection.[260] In *Washington v. Glucksberg*,[261] the Court held that the right to assistance in committing suicide is not a fundamental liberty interest protected by the Due Process Clause.[262] This case shows that people do not have an unlimited right to do with their bodies as they please and that the right to privacy in obtaining medical treatment may be limited by state interests.

2. Procreative Liberty and Parental Discretion Are Not Limitless Rights

Laws regulating any ART, especially PGD, develop slowly and may appear inadequate.[263] The value given to procreative liberty is at least a partial

258. *Id*. at 1485.

259. *Id*.

260. *See* Washington v. Glucksberg, 521 U.S. 702 (1997) (upholding a state law prohibiting assisted suicide).

261. *Id*.

262. *Id*. at 735. The Court observed that the Due Process Clause protects the fundamental rights and liberties that are "deeply rooted in this Nation's history and tradition." *Id*. at 720–21. Substantive due process cases require a '"careful description' of the asserted fundamental liberty interest. Our Nation's history, legal traditions, and practices thus provide the crucial 'guideposts for responsible decisionmaking.'" *Id*. at 721 (citations omitted). Because PGD is still a relatively recent development, the Court would probably not find a fundamental right for individuals to use it in any way. If this were allowed, it would essentially recognize a right to create a child. *See* Shawn E. Peterson, *A Comprehensive National Policy to Stop Human Cloning: An Analysis of the Human Cloning Prohibition Act of 2001 with Recommendations for Federal and State Legislatures*, 17 NOTRE DAME J.L. ETHICS & PUB. POL'Y 217, 240 (2003) (making a similar argument with human cloning).

263. Hecht, *supra* note 221, at 252–53, 256 (noting that this indicates that society is concerned about how, and if, such regulations should occur. Some medical societies and associations have published guidelines, but physician adherence is voluntary. Additionally, any current federal regulations regarding fetal experimentation and research do not cover the private sector.); *see also* Andrews & Elster, *supra* note 250, at 44 (noting that the United States "lacks an adequate structural mechanism for assessing genetic and reproductive technologies" and that several groups have begun to address this, such as the New York State Task Force on Life and the Law, the Assisted Reproductive Technologies and Genetics Committee of the American Bar Association, and the Institute for Science, Law, and Technology's Working Group on Reproductive Technologies); Malinowski, *supra* note 61, at 221 (commenting that the field of ARTs "has burgeoned into a major commercial and medical presence largely without the restraint of controlling regulatory checks").

explanation for the lack of regulatory oversight in the field of ART.[264] But the premium placed on procreative liberty may be mistaken and, regardless, must be tempered by social reflection, as "[t]raditional medical ethics . . . has relied on principles other than utility in determining what is and is not ethically appropriate in the practice of medicine in the research and therapeutic settings . . . ."[265] "[T]he decision about whether or not to procreate is most strongly attached to the decision about whether or not to become a parent."[266] Although parents are generally free to decide how to rear their children,[267] there is an absence of case law that addresses parental rights in terms of "unnecessary treatments, therapies, or surgeries."[268] With this in mind, it is possible to speculate that the Court might extend a right to procreate to at least some forms of ARTs, but it is doubtful that this right would extend to *all* medical procedures resulting in a child's birth.[269]

In Robertson's broad view of procreative liberty, "because a person may abort an embryo for any reason, a person may prenatally select or deselect traits for any reason"[270]—but this is a faulty analogy. A right not to procreate does not translate into a right to customize offspring. In *Roe v. Wade*,[271] the

264. *See* Malinowski, *supra* note 61, at 203–04 (also noting that another explanation is "the premium placed on autonomy in healthcare decision-making").

265. *Id*. at 204–05 (quoting A PRIMER FOR HEALTH CARE ETHICS: ESSAYS FOR A PLURALISTIC SOCIETY 193 (Kevin O'Rourke ed., 2d ed. 2000)).

266. Dana Ziker, *Appropriate Aims: Setting Boundaries for Reprogenetic Technology*, 2002 DUKE L. & TECH. REV. 11, 6 (2002), *at* http://www.law.duke.edu/journals/dltr/articles/2002dltr0011.html (stating that the interest in child rearing should be at the forefront when considering procreative liberty).

267. *See, e.g.*, Pierce v. Soc'y of Sisters, 263 U.S. 510 (1925).

268. Sherwood, *supra* note 251, at 643.

269. Coleman, *supra* note 215, at 66 (noting that although ARTs require medical intervention, that does not mean they automatically "fall outside the scope of constitutional protection"); *see also* Rao, *supra* note 228, at 1115 (stating that the right to bodily integrity does not "necessarily 'extend[] constitutional protection to noncoital methods of reproduction'" (quoting Rao, *supra* note 257, at 1485)); Sherwood, *supra* note 251, at 643 (suggesting the unlikeliness that parents can "demand and have a right to any and every treatment for their child"); Steinbock, *supra* note 9, at 186 (suggesting that factors to consider for the appropriateness of prenatal testing are impact on health, age of onset, probability of disease, and potential for therapy). "The case for morally permissible prenatal testing is strongest where there is serious impact on health, a high probability of disease, non-existent or ineffective therapy, and early age of onset." *Id*.; *see also* Ziker, *supra* note 266, at 7 (stating that the right to procreate should be limited to protect procreative interests that further the important interest of child rearing). *See generally* Botkin, *supra* note 249, at 288–90 (identifying various organizations and commentators that believe that a "line" should be drawn as to what kinds of information and tests should be offered for prenatal diagnosis and which should not be offered and stating that most would limit testing to serious conditions and exclude testing for "mild" or "trivial" conditions).

270. *See* Ziker, *supra* note 266, at 9 (citing Robertson, *supra* note 216, at 427). Ziker makes a legal distinction between abortion and selection by preimplantation genetic screening. *Id*. at 10.

271. 410 U.S. 113 (1973).

Court considered the balance between conflicting state interests and determined that the parental rights at stake, such as procreative liberty, personal autonomy, and bodily integrity, outweighed the state's interest in protecting prenatal life.[272] When considering PGD, however, many of the parental interests at stake in abortion disappear; thus, the constitutional validity of the screening will depend on the parents' interest in procreative liberty and the state's interest in protecting prenatal life.[273] Prenatal life arguably has some slight legal interests that should be balanced against the "heart of procreative liberty"—child rearing.[274] Therefore, the Court would likely allow the use of reproductive technology, and thus PGD, so long as it furthers the parental interest of child rearing, which has been recognized as a protected liberty interest.[275] As will be seen in the Sections below, not all uses of PGD further the important interest of child rearing.

3. How the Uses of PGD Might Be Distinguished

The Court is likely to differentiate procedures that enable individuals to have a child from procedures that seek to provide the means to have a *particular* child.[276] PGD can be regulated because it is not as closely connected to the decision of whether "to bear or beget a child"—its use relates more directly to the *type* of child the couple would have.[277] The right to "bear and beget a child" does not invoke a right to a "beautiful or talented child."[278] Couples who want to use PGD for non-therapeutic purposes can still decide

272. *See id.*; *see also* Thomas Stuart Patterson, Note, *The Outer Limits of Human Genetic Engineering: A Constitutional Examination of Parents' Procreative Liberty to Genetically Enhance Their Offspring*, 26 HASTINGS CONST. L.Q. 913, 928 (1999) (noting that the interests at stake in *Roe* were also based on personal autonomy and bodily integrity, and not merely procreative liberty).

273. *See* Patterson, *supra* note 272, at 928–29. "In the genetic engineering scenario, bodily integrity plays absolutely no role. The personal autonomy of the woman will not be affected by inability to genetically engineer her children. Thus, much of the rationale behind the decisions in *Roe* and *Casey* fails to support Robertson's assertion." *Id.* A similar analogy can be made for using PGD for non-therapeutic purposes. Prohibiting couples from using PGD for arbitrary purposes will not affect their personal autonomy.

274. Ziker, *supra* note 266, at 12–13 (recognizing that criminal law and inheritance law identify the interests of even a pre-viable fetus).

275. *Id*. at 14. *See generally* Savulescu, *supra* note 197.

276. Coleman, *supra* note 215, at 66.

277. Vicki G. Norton, Comment, *Unnatural Selection: Nontherapeutic Preimplantation Genetic Screening and Proposed Regulation*, 41 UCLA L. REV. 1581, 1628 (1994).

278. *Id*. at 1629; *see also* Andrews & Elster, *supra* note 250, at 62 ("Even though parents have a constitutional right to make child rearing decisions similar to their constitutional right to make childbearing decisions, parents do not have a right to receive genetic information about their children that is not of immediate medical benefit.").

whether or not to have a child even if the technology was not available.[279] Thus, parents attempting to use PGD for non-therapeutic reasons are trying to invoke more than their interest in the right to procreation.[280] When considering restricting trait selection technologies, the Court is "likely to ask whether such restrictions are substantial limitations for the average person seeking to have a child, not whether they interfere with the willingness of particular persons to reproduce."[281]

Under this narrower view of procreative liberty, the right to procreate would only protect using PGD for traits that substantially affect the responsibilities associated with child rearing.[282] Clearly, a couple that seeks to prevent offspring with a severe genetic disease should be allowed access to PGD.[283] Using PGD for sex selection should be prohibited because the gender of a child does not substantially affect child rearing responsibilities.[284]

Screening for non-medical or non-therapeutic traits does not substantially affect child rearing responsibilities and thus should not be allowed. In general, "[a]voiding serious [genetic] diseases constitutes a compelling objective for [PGD]. Pursuit of the perfect baby through nontherapeutic genetic enhancement does not."[285] Although most parental decisions are viewed with great deference,[286] PGD can allow parents to determine their children's gender and other characteristics, which clearly plays an influential and perhaps even permanent role in their overall development. Such decisions should *not* be

279. Norton, *supra* note 277, at 1628–29 (noting that the denial of access to PGD would only "seriously affect" the bodily integrity and personal autonomy of the at-risk couple and that denying such access to healthy and nonfertile couples would only affect their bodily integrity by creating disappointment if they wanted to select their children's traits); *see also* Coleman, *supra* note 215, at 66 (stating that even if Robertson's notion that restrictions on trait selection would affect some couples' willingness to have children, "the Court is unlikely to find that such indirect burdens on procreative decisions are constitutionally significant").

280. *See* Norton, *supra* note 277, at 1621–22 (suggesting that the Court is likely to find a right to affirmative procreation, and possibly even IVF, but less likely to find a separate liberty to use preimplantation genetic screening, a technology that is even more specific than IVF). For a complete examination of a couple's interests in using IVF, see *id*. at 1624–28.

281. Coleman, *supra* note 215, at 67.

282. Ziker, *supra* note 266, at 19 (acknowledging that the "substantially affects" component of the test is difficult and uncertain). Ziker concludes that at times the test will require subjective judgment because it is not a bright-line test. *Id*. "Nevertheless, drawing a line that becomes blurred in borderline cases should not deter courts from drawing the line at all." *Id*.

283. Screening for late-onset genetic diseases and susceptibility traits would arguably not be allowed, as the extra responsibilities do not arise until later in life. But, some might allow PGD for these disorders by arguing that child rearing responsibilities are indefinite. For more discussion on this point, see Ziker, *supra* note 266, at 20–21.

284. Screening for sex-linked diseases has not been addressed in this Comment but could arguably be permitted.

285. *See* Ziker, *supra* note 266, at 23.

286. *See supra* note 242 and accompanying text.

given deference—public policy and the "best interests of the child" demand that parents' rights be limited in this area.[287]

Legislation for any ART, including PGD, must be realistic and rational, instead of merely attempting to suppress a controversial technology.[288] New technologies should be introduced cautiously, as a prudent approach will ensure that it is not abused.[289] The potential danger of non-therapeutic uses of PGD has warranted the regulation of the technology.

C. Regulation of PGD is Necessary from a Public Policy Perspective

Although procreative liberty is arguably not broad enough to allow a couple to use PGD for any purpose, there are nevertheless strong reasons for regulating it from a public policy perspective. Present scientific and cultural trends support the assumption that prospective parents will use PGD to the fullest extent that their financial resources allow.[290] Thus, legislation must be enacted to regulate PGD based on the parental intent for the procedure, thereby preventing "the development of a full-blown free market genetic catalogue that is available only to those who can afford it."[291]

287. *See, e.g.*, Stanley v. Illinois, 405 U.S. 645, 652 (1972) (recognizing that the state can exercise its legitimate interests of protecting the physical, emotional, and mental welfare of a minor child and the best interests of the community).

288. Hecht, *supra* note 221, at 235 (suggesting that previous legislation regarding reproduction issues was "motivated by an aversion to the 'nightmarish and decidedly unnatural perversion of human reproduction'" (citation omitted)); *see also* Norton, *supra* note 277, at 1642 (noting that there must be a "rational relationship between the ban [on non-therapeutic preimplantation genetic screening] and a legitimate state interest"). State and society interests are discussed *infra* Part IV.C.1.

289. *See* John A. Robertson, *Preconception Gender Selection*, 1 AM. J. BIOETHICS 2, 7 (Jan. 2001) (recognizing that, in terms of sex selection, a desired policy would restrict the practice to offspring gender variety until further debate and analysis of the issues occurs, as opposed to making the technology immediately available to anyone desiring it), *at* http://juno.ingentaselect.com/vl=7391710/cl=52/nw=1/fm=docpdf/rpsv/cw/mitpress/15265161/v1n1/s2/p2.

290. Malinowski, *supra* note 61, at 205 (noting the example of upper and middle-class families to get their children into the "right" preschools and elementary schools in order to give them early advantages). *But see* Robertson, *supra* note 216, at 452 (stating that because "there are probably few fertile couples who would go through IVF and PGD just to select offspring genetic characteristics" and because the costs of PGD are likely to deter most couples who are otherwise undergoing IVF from also seeking gender selection, PGD is unlikely to affect gender role ratios, cause discrimination to women or people with disabilities, or lead to other consequences). This notion is dated, as information stated earlier shows that couples have begun to use PGD solely for sex selection. *See supra* Part II.D.3.

291. Karen E. Adams, *Ethical Considerations of Applications of Preimplantation Genetic Diagnosis in the United States*, 22 MED. & L. 489, 494 (2003); *see* Hecht, *supra* note 221, at 256 (suggesting that "[w]ithout legal guidance on fetal screening, genetic enhancement may 'evolve' unchecked into a New Age eugenics movement where only the strongest and smartest babies are brought into the world"); *see also* FUKUYAMA, *supra* note 18, at 208 (noting that preimplantation

Drafting legislation regulating the therapeutic uses of PGD will prevent children from being viewed as commodities, which will likely occur if parents select desired, but non-therapeutic, traits.[292] It is troubling to think that the only way some couples would conceive is if they could have a child of a particular gender or with a particular physical or performance trait.[293] While family balancing is an understandable desire among couples who want to use PGD solely for sex selection, they should want to nurture and rear a *child*, not a *boy* or a *girl*. It is especially troubling to consider that some couples would spend the necessary thousands of dollars for the procedure to create their *first* child. Because parents now have the opportunity to permanently affect an aspect of a child's life, it would be cautious and wise to limit this authority to therapeutic uses. Such an approach would still grant parents the deference to make medical decisions on behalf of their children.[294] Furthermore, legislation that only allows the therapeutic uses of PGD will aid society's interest in preventing harm to at-risk families by minimizing the significant emotional, physical, and financial burdens they could endure.

The interests of couples wishing to control genetics during their procreation must be tempered against the broader interests of society.[295] PGD raises the issue of negative versus positive eugenics.[296] Most people might

diagnosis and screening does not need to be banned, but rather should be regulated by distinguishing between therapy and enhancement). "This general principle would allow us to use biotechnologies to, for example, cure genetic diseases like Huntington's[,] chorea[,] or cystic fibrosis, but not to make our children more intelligent or taller." *Id*. at 208–09. In cases where it is hard to make those distinctions, regulatory agencies should be able to make them. *Id*. at 209–10.

292. *See supra* notes 84–140 and accompanying text.

293. Although the findings from the Australian survey discussed in Part IV.C. indicate that females might not be as oppressed by sex selection as some commentators have speculated, the potential for such a problem is still frequently discussed in the literature. *See, e.g.*, Sonia Mateu Suter, *The Routinization of Prenatal Testing*, 28 AM. J.L. & MED. 233, 269 (2002) (noting that as it becomes more possible to select or alter traits without pregnancy termination, the pressure to select desirable traits will increase and that "[i]n gaining the choice to control the quality of our children, we may rapidly lose the choice not to control the quality, the choice of simply accepting them as they are" (citation omitted)).

294. Sherwood, *supra* note 251, at 644.

295. PAUL, *supra* note 93, at 135.

> Indeed, if we insist on absolute reproductive autonomy we must accept the use of genetic technologies to prevent the birth of those who are unwanted for any reason: that they will be the "wrong" gender, or sexual orientation, or of short statute, or prone to obesity, or . . . . Used this way, medical genetics will surely reinforce a host of social prejudices. A history of eugenics that is sensitive to its complexities alerts us to the fact that genetic technologies present more than one kind of danger—and that if we are not very careful, we may avoid one only to court another.

Id.

296. Chambers, *supra* note 225, at 418 (describing "negative eugenics" as the elimination of diseases or defects and "positive eugenics" as the enhancement of traits); *see also* FUKUYAMA,

consider PGD to be positive eugenics (or genetic enhancement), but any form of embryo selection could arguably involve both positive and negative eugenic decisions.[297] As noted, a potential fear is that if PGD was widely available, it would exacerbate class differences, as couples with money and inclination would give their offspring further advantages that others did not have.[298] PGD could also decrease genetic diversity—as certain traits become popular, parents will select them and the pool of overall genetic traits might begin to decrease.[299] Similarly, the government might also have an interest in preventing discrimination against pre-embryos.[300] PGD and other genetic enhancement technologies may also alter family relationships and dynamics. A primary concern is the risk that the child will be viewed as a "product or commodity engineered to satisfy parents."[301] Children may suffer

supra note 18, at 85–87 (discussing eugenics in the United States and the West); Wilder, *supra* note 101, at 203.

> Arguably, assisted reproduction is a method of eugenics, pure and simple. The demand for assisted reproduction exists because people want to have, raise, and be succeeded by, children with a genetic make-up that is viewed by them as more desirable than that which would be possessed by another child.

Id.; *see also* Roberts, *supra* note 23, at 5 (noting that the "laissez-faire approach currently practiced in the United States—while allowing for individual agendas of reproductive choice based on religion, culture, philosophy, and wealth—leaves open the door to eugenic practices, and could ultimately exacerbate the rift between the affluent and the underprivileged").

297. Chambers, *supra* note 225, at 418 (noting that even the elimination of embryos with devastating defects involves both types of eugenic decisions because "to say no to one embryo is, in most situations, to say yes to another, thereby favoring the 'better' embryo, a positive eugenic decision."). *See generally* King, *supra* note 41.

298. ROBERTSON: CHILDREN OF CHOICE, *supra* note 219, at 166 (noting that this would "creat[e] more unfairness than the natural lottery already creates"); *see also* Norton, *supra* note 277, at 1611 (noting that the ability to screen more embryos could accelerate the formation of a "genetically elite class"). *See generally* Mehlman & Rabe, *supra* note 58, at 182–83 (suggesting that genetic enhancement compromises fairness because not all members of society have equal access to the technologies and those that are genetically enhanced may have unfair advantages over the un-enhanced members and that such technologies also threaten democracy and harm society's respect "for the value of humanity and the genetic heritage of mankind").

299. *See* Norton, *supra* note 277, at 1613; *see also* Mehlman & Rabe, *supra* note 58, at 184 ("There is also a fear that [genetic enhancement] may change the genetic pool of the human race.").

300. *See* Norton, *supra* note 277, at 1644 (suggesting that "the state interest in the equal treatment of the early pre-embryo would be subordinate to the rights of a born person").

301. ROBERTSON: CHILDREN OF CHOICE, *supra* note 219, at 160; *see also* Ziker, *supra* note 266, at 15–16 (noting that prenatal genetic screening is much different from post-natal molding of offspring because the former leaves a permanent mark on offspring); FUKUYAMA, *supra* note 18, at 93–94 (recognizing the argument that parents can make decisions on behalf of their children, but noting that these children who are reared in a certain way can rebel later and pointing out that genetic modification, on the other hand, "is more like giving your child a tattoo that she can never subsequently remove and will have to hand down not just to her own children but to all

psychological harm knowing that they were designed and manufactured.[302] As previously mentioned, the concern is that the children would experience enormous pressure in trying to meet their parents' expectations and would be unable to devise their own preferences. This could result in "conditional parenting," in which children live out the possible self-serving preferences of their parents.[303] Similarly, society's expectations of parental responsibility might shift so that "good parents" are expected to give their children the right genes and traits.[304]

D. Who Should Regulate PGD?

In March 2004, The President's Council on Bioethics issued a report entitled *Reproduction and Responsibility: The Regulation of New Biotechnologies*.[305] The report included the findings of "a comprehensive inquiry into the current regulation of [the] biotechnologies that touch on human reproduction."[306] Interestingly, the Council noted that:

> [t]he Council finds that our regulatory institutions have not kept pace with our rapid technological advance. Indeed, there is today no public authority responsible for monitoring or overseeing how these technologies make their way from the experimental to the clinical stage, from novel approach to widespread practice. There is no authority, public or private, that monitors how or to what extent these new technologies are being or will be used, or that is responsible for attending to the ways they affect the health and well-being of the participants or the character of human reproduction more generally. Our existing regulatory institutions, such as the Food and Drug Administration or local institutional review boards, do not at the present time oversee this area, and the welcome ethical standards promulgated by the professional societies are somewhat limited in scope and not binding on individual member practitioners. *Yet the Council has refrained, at least for the time being, from proposing major new regulatory institutions. Gaps in our current information*

subsequent descendants"); Steinbock, *supra* note 9, at 185 (briefly discussing the views of some commentators about the potential commodification and objectification of children).

302. *See* Lori B. Andrews, *Is There a Right to Clone? Constitutional Challenges to Bans on Human Cloning*, 11 HARV. J.L. & TECH. 643, 653–54 (1998) (suggesting such effects on cloned children); *see also* Mehlman & Rabe, *supra* note 58, at 184 (speculating whether children would reproach parents for making bad decisions on their behalf).

303. Jennifer Fitzgerald, *Geneticizing Disability: The Human Genome Project and the Commodification of Self*, 14 ISSUES L. & MED. 147, 158 (1998).

304. Mehlman & Rabe, *supra* note 58, at 184.

305. The President's Council on Bioethics, *Reproduction and Responsibility: The Regulation of New Biotechnologies* (Mar. 2004), *at* http://www.bioethics.gov/reports/reproductionand responsibility/_pcbe_final_reproduction_and_responsibility.pdf [hereinafter *Reproduction and Responsibility*].

306. *Id*. at xvii.

> *make doing so premature, and our deep differences over the moral status of human embryos make it problematic*.[307]

Although the Council correctly recognized that American regulatory institutions are lagging in this area, its decision to postpone proposing new institutions is unacceptable. The combination of ART and the genetics revolution requires the government to assume a "more meaningful role."[308] PGD demands particular attention. The Council's recommendation to "[r]equire more specific reporting and publication of the frequency of, and reasons for, uses of . . . [PGD]" is not enough.[309] The government must enact legislation as a prerequisite to establishing institutions with legitimate enforcement powers, as England has done.[310] The legislation should create "sufficient regulatory jurisdiction over this technology implemented by those with scientific expertise, who should become directly engaged in ART through the dynamism of ongoing regulation reflective of the changing nature of the underlying science and public opinion."[311] Ideally, a new regulatory agency similar to the HFEA in England would be created. This agency should focus exclusively on PGD and other reproductive technologies. This organization will undoubtedly take some time to establish, so one suggestion in the

307. *Id.* (emphasis added).

308. Malinowski, *supra* note 61, at 214; Wilder, *supra* note 101, at 203 (suggesting that state regulation of the medical practice of assisted reproduction "be limited to ensuring safe and ethical practices, without attempting to influence the character of the genome itself," but recognizing "the distinction is not always an easy, or even possible, one"). *But see* Botkin, *supra* note 249, at 265–66 (proposing medical professional standards as a desired alternative to government regulation of assisted reproduction). For a discussion of the pros and cons of a number of possible options for regulating PGD, including federal, state, and non-governmental approaches, see *A Discussion of Challenges*, *supra* note 36, at 11–17.

309. *Reproduction and Responsibility*, *supra* note 305, at xlvi.

310. Malinowski, *supra* note 61, at 216; *see also* FUKUYAMA, *supra* note 18, at 203–04 (noting that it is no longer enough for the government to appoint national commissions to deal with biotechnology questions and that "it is time to move from thinking to acting, from recommending to legislating. We need institutions with real enforcement powers."). *But see generally* John A. Robertson, *Procreative Liberty and Human Genetics*, 39 EMORY L.J. 697, 715–18 (1990) (discussing potential roles of the United States government and suggesting that they be negative or noninterfering. The government has a duty is to refrain "from barring persons from obtaining and making use of genetic information in reproduction." The government also has a regulatory role to protect consumers of genetic information by assuring them that the information is provided by competent professionals. Another governmental role is to provide access to genetic services to those people who lack the resources or knowledge to obtain it themselves.).

311. Malinowski, *supra* note 61, at 216 (suggesting that if people with technical scientific expertise were given the authority, it may also be possible to draw distinctions between therapy and enhancement, with greater restraints imposed on enhancement).

meantime is to expand the role of the Food and Drug Administration ("FDA").[312]

The federal government has been slow to respond to this new technology, and the report issued by The President's Council on Bioethics will unfortunately not prompt major action anytime soon. Because it appears that the federal government is likely to continue its position of no regulation over PGD and other ARTs, the individual state governments should become involved in this process and impose regulations. Even Robertson acknowledges that both state and private actors can "express their own moral views about reproductive choice" or "take steps to minimize perceived harm."[313] The state can deny funding to ART procedures or refuse to provide the required legal infrastructure to make efficient use of the procedures.[314] If the state does decide to allow certain forms of ART, it should certify and license laboratories and providers.[315] Federal regulation would be more ideal because of its uniformity and as shown could arguably withstand constitutional challenge, but given the federal government's prior reluctance to get involved in this arena, the states should, at a minimum, implement some of the discussed regulations.

Finally, if both federal and state governments refuse to get involved, the private associations that accredit and inspect the fertility clinics should attempt to authorize certain uses of PGD. These associations should follow the guidelines issued by the ASRM, assuming that Congress does act to authorize a new agency to oversee PGD. It would be in society's best interest to take some sort of action to prohibit couples from using PGD in any manner they choose.

312. *Id*. at 218 (suggesting that the FDA's definition of tissue products regulated as biologics should be expanded to include the manipulation of sex cells in any manner, manipulation through hormone therapy, or the creation of embryos as tissue products). *Id.* at 219; *see also* Mehlman & Rabe, *supra* note 58, at 190–92 (suggesting several different agencies and ways that the government could regulate genetic enhancement, including the FDA); *A Discussion of Challenges*, *supra* note 36, at 7–9 (identifying the CDC, FDA, and Center for Medicaid and Medicare Services as agencies that currently oversee areas relating to PGD). *But see* FUKUYAMA, *supra* note 18, at 212–15 (suggesting that existing institutions, including the FDA, may not be able to assume such a role and that a new agency is needed instead).

313. Robertson, *supra* note 232, at 915 (suggesting that doctors can opt not to perform certain procedures and impose limits on procedures they are willing to perform). *But see A Discussion of Challenges*, *supra* note 36, at 9 (discussing how no state has enacted a law that directly addresses PGD and that most states have not assumed oversight responsibilities for fertility clinics). This report identifies the pros and cons of a number of proposed policy options. *See id*. at 11–17.

314. Robertson, *supra* note 232, at 915; *see also A Discussion of Challenges*, *supra* note 36, at 9 (suggesting that states can influence access to PGD by mandating insurance coverage).

315. Robertson, *supra* note 232, at 915; *see also id.* at 919 (stating that "any doctor can provide infertility services without any specific certification if he or she attracts patients and has access to surgical suites for egg retrieval").

V. CONCLUSION

PGD is a powerful and controversial technology that has revolutionized genetic testing and assisted reproduction while helping families worldwide. The scope and uses of PGD, as well as the ethical and legal issues surrounding it, have greatly increased since it was first developed. As the technology further refines itself and our scientific understanding improves, researchers are likely to develop even more genetic tests that utilize PGD. This potential expansion coupled with an increase in public awareness of PGD could certainly increase demand for the technology. In time, couples might have the opportunity to choose a number of their children's traits for arbitrary reasons, and the United States does not currently have any legislation to prevent this from occurring. Other nations have assumed a more active role in regulating this technology, and the United States should as well. The Supreme Court has not recognized that the rights of procreative liberty and family discretion extend so far as to protect all parental decisions relating to preconception selection. Prior decisions relating to contraception, abortion, and family do not incorporate a right for couples to use assisted reproductive technologies in any way they please. If no regulatory measure is taken, individuals could soon find themselves "liv[ing] in a society where one's genetics become more a matter of choice than chance."[316] We do not want to live in a society where "discrimination [is] down to a science."[317] Unregulated use of PGD could result in serious harm to society and children, making it necessary to assume control over the technology and ensure that it will be used only for therapeutic purposes.

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316. *A Discussion of Challenges*, *supra* note 36, at 5.

317. GATTACA, *supra* note 1.

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